FAMILY BASED MEMORY REHABILITATION

FOLLOWING SEVERE CLOSED HEAD INJURY

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The use of the memory checklists devised in the study is described in a chapter to be published:

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ABSTRACT

Family and other social support is increasingly being recognised as a necessary component for comprehensive rehabilitation of the head injured. This study investigates the potentially constructive roles for relatives as co-therapists in ameliorating problems that persist after discharge from hospital and in-patient rehabilitation, if available. These are:-

(a) As a source of information to help delineate the patient's problems.

(b) As co-therapists, taking part in the planning and process of treatment.

Four memory aids/mnemonics were devised and adapted from the literature on cognitive remediation aimed at reducing day-to-day memory problems. A multiple baseline design was used.

The results suggest that relatives have a potential value in helping to achieve generalisation of memory techniques to real life environments.

Single case studies highlight the principles and practicalities of intervention, and the issues of family dynamics that arise during the course of treatment.

CHAPTER I

Introduction to the Present Study

Introduction

Serious head injury is one of the most common causes of disability in young adults in the westernized world (Rimel and Jane, 1983). In the U.K., it is estimated that 150 people experience major disability resulting from head injury per 100,000 population (Field, 1976). Survivors are most likely to be young adults who thus may have many years of disability ahead of them (Jennett and McMillan, 1981).

Memory disorders are among the most characteristic sequelae of traumatic brain injury (Deelman and Saan, 1990). Their frequent persistence and the difficulties they cause create a significant barrier to the resumption of normal life (Brooks et al, 1987). Their importance is further heightened by their contribution to the degree of stress borne by relatives, and often occurring with emotional and behavioural problems, they tend to overshadow the lesser impact of physical disability (McKinlay et al, 1981).

In recent years, there have been increasing clinical and research efforts to develop rehabilitation strategies which aim to alleviate the problems resulting from memory problems following severe brain injury. Attempts have been aimed at reinstating memory processes and teaching compensation strategies for poor memory. Despite some gains on formal testing, results have often been disappointing in terms of real-life gains, as subjects tend to forget to use methods which may themselves require considerable cognitive ability (Gloag, 1985). Studies highlighting functional performance in everyday life, as opposed to measures based on formal cognitive assessment, have provided a means of identifying the memory problems which have daily significance to the patient, as well as to those in the care and/or treatment of

the head injured (Sunderland, Harris, and Baddeley, 1983, Wilson, 1987).

The importance of family and other social support in head injury rehabilitation is also increasingly being recognized, and some attention has been directed to helping families not only cope with problems of adjustment to the cognitive and behavioural effects of severe head injury, but to be actively involved in the rehabilitation process (Anderson and Parente, 1985).

In this context, the present study addresses the question of whether severely head-injured individuals, seen on an out-patient basis, can learn simple mnemonic strategies, devised to target the everyday memory problems as reported by patients. In order to achieve generalization, relatives are trained to act as co-therapists, while also acting as a source of information to help delineate the patients' problems. Finally the effect of treatment on the well-being of both patients and relatives is considered, and discussed in relation to individual cases.

CHAPTER II

Epidemiology of Traumatic Brain Injury

CHAPTER 2

EPIDEMIOLOGY OF TRAUMATIC BRAIN INJURY

Severe head injury is a major cause of disability in young adults. It has been estimated that there are 7,500 severe head injuries in the United Kingdom each year (Lewin, 1970) and that 1,000 - 1,500 people are severely disabled (Newcombe, 1982). The prevalence of post-head injury disability in the community has been estimated to be as high as 150 per 100,000 (Jennett, 1983). A high proportion of those who are severely injured are young adults, many of whom are males at the start of their working lives with families to support (Field, 1976).

In the United Kingdom, head injury results in nine deaths per 100,000 population per annum. Almost fifty percent of these deaths are accounted for by road traffic accidents (RTAs) and the greatest number of these victims are young men, between fifteen and twenty four years of age (Jennett & McMillan, 1981). Between two to three hundred of every 100,000 of the population are hospitalised as the result of head injury each year and most of these remain in hospital for at least forty eight hours (Field, 1976).

Causes of head injury vary in distribution according to severity, age and sex (Jennett & Teasdale, 1981). Cultural differences have also been identified and in Scotland, for example, assault is as common a causal factor as a road traffic accident in leading to emergency admission of men aged fifteen to sixty four (Miller, 1986). The use of alcohol as a contributing factor is complex, being more common in those who are admitted to hospital as those sent home, and is more common in cities than elsewhere. Men are twice as likely as women to have alcohol detected following

a head injury (Jennett & Teasdale, 1981). In Scotland, it is more commonly found in injured pedestrians and as the result of assault or falling, than due to a road traffic accident. Generally, road traffic accidents, assaults and falls are the most common cause of severe closed head injury, while sporting accidents, birth trauma and industrial accidents are important minor sources of trauma compared to the first three (Crockard, 1981).

Cross-cultural comparisons of the incidence of accidents show a decrease in the number of head injuries in the USA and UK since the mid-1970's, while an increase has been found in Italy and West Germany (Jennett and Teasdale, 1981). Road safety laws requiring the use of safety belts and motorcycle helmets have helped to reduce the numbers (Bigler, 1987).

A smaller number of head injuries are due to sports injuries, where they are mainly found in boxing. Head injuries associated with sports tend to be mild but can lead to epilepsy and deafness. (Jennett & Teasdale, 1981).

Defining Severe Head Injury

The range in severity of head injuries, from insignificant blows on the head to severe impacts resulting in immediate death, make definition of head injury problematic. Field, (1976) defines head injury simply as an 'insult which carries some risk of trauma to the brain'. An alteration in the level of consciousness has been the traditional 'benchmark' of definitions of brain injury (Bigler, 1987)

In the past, severity has been measured in non-standard ways which have included the period of unconsciousness and of hospitalisation. More recently, efforts to accurately assess severity have resulted in the development of standardised scales, including (1) The Glasgow Coma Scale

(GCS), and (2) Duration of Post-Traumatic Amnesia (PTA).

The Glasgow Coma Scale (GCS) (Teasdale & Jennett, 1974) was the first empirically substantiated and clinically validated rating scale to quantify level of consciousness. It can be used to describe all post-traumatic states of altered consciousness, ranging from mild confusion to deep coma. The GCS evaluates three components of wakefulness independently of one another: (a) eye opening, (b) verbal response, and (c) best motor response. The scores of the highest score in each dimension are calculated from 3 to 13. GCS ratings offer some index of level and severity of brain damage on admission to hospital, and a score of 8 and above is suggested to predict good outcome (Jennett, 1975; Levin, Grossman et al, 1979). The relationship is not simple, however, and Lobato et al (1986) suggest that a low GCS can be tempered when there is a normal CT scan. Walsh has described the GCS as being 'far too coarse to be of significant value' (Walsh, 1985).

Post-Traumatic Amnesia is defined as 'the period after impact during which new information is not registered and stored so that there is a failure of continuous memory of ongoing events' (Editorial, The Lancet, 1961). Post-Traumatic Amnesia is often described as 'the best yardstick we have' for measuring the severity of closed head injury, and together with the Glasgow Coma Scale has become widely used in charting recovery from closed head injury and in predicting outcome.

Russell (1971) suggests that the significance of Post-Traumatic Amnesia can be measured by the following parameters, where 'concussion' indicates significant trauma rather than merely slight injury:

PTA of less than 1 hour is equal to 'mild' concussion.
PTA of 1 - 24 hours is equal to 'moderate' concussion.

PTA of 1 - 7 days is equal to 'severe' concussion.
PTA of more than 7 days is equal to a 'very severe' concussion.

Jennett (1976) has added the category 'extremely severe' concussion to apply when PTA is more than one month.

The concept of Post-Traumatic Amnesia has been reviewed by Teasdale and Brooks (1985). PTA is defined as the time after injury which cannot be substantially recalled by the patient. 'Islands' of memory do not count as signalling the end of PTA; it is the recovery of continuous memory which marks the end of PTA, and assumes that the patient is alert, functioning, but has difficulty retaining and processing new information (anterograde amnesia). Retrograde amnesia for the period preceding the accident may also be apparent. Jennett & Teasdale (1981) demonstrated the significance of PTA. Reporting on 486 patients six months post-injury, they noted that while 83% of those with less than 14 days of PTA made a 'good recovery' only 27% of those with over 28 days of PTA did so.

However, it must be noted that their definition of 'good recovery' is a broad one and needs by no means imply freedom from neuropsychological and personality changes of some significance. Indeed, a number of studies have shown that PTA of over 1 week (very severe injury) is associated with poor outcome and persistent cognitive deficits (Brooks, 1983). However, it is a risk to expect too much specificity from ratings as even a PTA of five minutes - 1 hour (mild head injury) has been associated with significant brain injury (Brooks, 1983; Jennett, 1986).

The recent development of imaging procedures such as computer axial tomography (CT) and magnetic resonance imaging (MRI) enables patients to be evaluated in regard to the anatomical (CT and MRI) and electroencephalographic (EEG) basis of trauma. These are now usually used in tandem with the above measures to provide information regarding severity.

Head injury management has progressed considerably as a result of the introduction of both CT and measures of severity. In a recent study, Miller and his colleagues (1992) reported on head injury management spanning a 9-year period in a single regional centre, from where the patients included in the present study were drawn. The authors examined admission rates, pattern of referral and the prevalence of multiple injuries. In addition, the usefulness of CT in detecting intracranial haematoma was assessed. They found that the implementation of guidelines for admission and referral were of benefit to head injury management. Use of Glasgow Coma Scale scores (GCS) led to a reduction in the numbers of head injury admissions over the nine years, and more liberal use of computed tomography resulted in detection of a greater number of intracranial haematomas, most of which were found in non-comatose patients. They also found a reduction in the early mortality rate, which fell from 45 per cent to 34 percent. It appears that, while the number of severe head injuries has held steady, the admission rates of patients with minor head injury fell from 1616 to 702, with moderate injuries varying. This study demonstrates the value of the concept of head injury centres, based on regional neurosurgical units which can provide pre-emptive management.

(Miller et al, 1992).

The Nature of the Population

Difficulties of definition and diagnosis of severity of head injury weaken the precision with which estimates of survivors of head injury can be made. But it is well established that severe head injury commonly results in disability, especially in the first thirty years of life, and a considerable fraction of survivors remain disabled. It is unclear to what, if any, extent the increased survival rate resulting from modern acute medical care has been paralleled by reduced morbidity (Newcombe, 1982). In view of the young age of victims, the length of lasting disability is considerable.

Head injury does not strike at random. This group has been found to be predominantly male rather than equally divided between the sexes (Field, 1976), and perhaps as much as the ratio 4:1 for adults, although the age distribution appears very similar within each sex. There also tends to be a bias towards the lower social classes (Field, 1976).

Taken together, the studies above depict victims of severe head injury as young male adults, who have sustained injuries in road traffic accidents, or as victims of assault (Jennett & Teasdale, 1981). Alcohol has been found to be a contributing factor and they are more likely to come from a lower socioeconomic group (Galbraith et al, 1976). They are thus very likely to be at an age where they are expected to be establishing more independent lives from their parents, developing permanent relationships and maybe have young families and most importantly, perhaps, have many years of active life ahead of them. It therefore seems essential that these characteristics are taken into consideration by those planning services for head injured individuals, as the impact of the injury and its cognitive and behavioural

effects may have far outreaching consequences to both the patient and his/her family.

CHAPTER III

Neuroanatomical and Neuropathological Effects

CHAPTER 3

NEUROANATOMICAL AND NEUROPATHOLOGICAL EFFECTS

To best understand the cognitive and behavioural sequelae of cerebral injury, a consideration of the pathology is vital. Typically, the cognitive and behavioural effects of the brain injury relate directly to the actual brain sites and systems involved, although there is typically a degree of non-specific impairment as well. By knowing these areas and extent of damage, some predictive value may be gained concerning the behavioural and cognitive outcome from brain injury. First, what constitutes a severe head injury will be defined, and this will be followed by an overview of the neuropathology of cerebral trauma. What we now know of the mechanisms of cerebral trauma has been greatly enhanced by technological improvements that allow the in-vivo visualisation of the brain. In addition, it has enabled modern management of brain injury to be directed at the rapid implementation of diagnostic methods, in order to minimize brain ischemia (Miller, 1991).

The Nature of the Damage

A number of mechanical forces involved in closed head injury have been identified and help us to understand many of cognitive and behavioural symptom patterns which can follow (Gurdian & Gurdian, 1978; Grubb & Coxe, 1978).

The areas of the brain most frequently cited as particularly vulnerable to the effects of craniocerebral trauma include the prefrontal region of the frontal lobes, the anterior portion of the temporal lobes, in addition to brain stem

structures (Walsh, 1978, Prigatano et al, 1986). These areas are prone to contusion, but other types of brain injury also occur. Ischaemic injury can occur, involving brain tissue becoming deprived of blood. Graham, Adams & Doyle, (1978) noted that brains studied at post-mortem after severe craniocerebral injuries had evidence of ischaemic brain injury. A very high incidence of involvement of hippocampal and basal ganglia structures (88% and 80% respectively) was also found. The importance of these findings lies in their emphasis that deep brain structures which are either part of, and closely connected with, the temporal and frontal lobe systems are quite vulnerable to impairment following such injuries.

The region anterior to the hippocampus is recognised for its role in the interruption of ongoing behaviour for survival value (Prigatano et al, 1986). Its increased risk in craniocerebral trauma may particularly account for the reported increased emotional lability, including decreased drive and increased irritability following severe head trauma. The impact on this region will be discussed in more detail after an initial description of the direct and indirect effects of severe trauma to the brain.

Direct Effects

Direct and primary effects are those which are associated with the trauma itself. These include contusion and bruising, shearing and laceration, and haemorrhage or combinations of these.

The most outstanding mechanism is that of the force of impact in which a relatively still victim receives a blow ('coup') to the head. Damage results from the inward depression of the skull at the point of impact, and the

consequent compensatory outbending in adjacent areas. Skull fracture may occur, raising the possibility of infection and further tissue damage. Contrecoup injuries involve contusion in the opposite area and are the predominant type of damage in occipital injuries (Grubb and Coxe, 1978). Contrecoup injuries are a common result of focal injuries to the side of the head (Smith, 1974; Roberts, 1976) and result from the force of the brain literally bouncing off the opposite side of the skull, due to its position as a flexible stem in a liquid medium (Gurdjian, 1975). Both coup and contrecoup injuries are a major cause of the quite specific and localised behaviour changes often resulting from severe closed head injuries.

Rotational acceleration is another force resulting in brain damage occuring in closed head injury (Jurko, 1979). In this, the brain moves rotationally within the skull, straining nerve fibres and blood vessels to the point of shearing (Strich, 1969). These microscopic lesions occur throughout the brain (Oppenheimer, 1968) but it is their tendency to be concentrated in the frontal and temporal lobes (Grubb and Coxe, 1978) which gives them neuropsychological significance. The fronto-temporal concentrations of contusional injury has been confirmed frequently (Gurdian, 1975).

Rotational velocity also appears to play a significant role in producing concussion (loss of consciousness) and it has been suggested that involvement of the brain stem reticular formation is required to produce concussion (Ommaya and Gennarelli, 1974).

Indirect secondary lesions may also arise after the event, and have a major role in the patient's outcome. These include ischaemia, anoxia, oedema and brain distortion due

to intracerebral bleeding.

Indirect Effects

In addition to direct cerebral damage on impact, significant physiological changes in blood pressure, heart rate, breathing etc. also occur and enhance the effect of the injury on cerebral functioning (Jennett & Teasdale, 1981).

These physiological processes which are consequent to the immediate impact of the injury have been identified as potentially at least as destructive of brain tissue as the direct effects (Grubb and Coxe, 1978; Jennett and Teasdale, 1981).

Because this damage is potentially avoidable or at least partly reversible, much attention is paid by neurosurgeons to secondary brain injury (Miller, 1991), and modern head injury management aims to detect as early as possible the mechanisms that can be responsible for secondary brain damage, and to pre-empt or reverse these mechanism. (Miller, 1991).

Haemorrhage is a common secondary source of damage. A haematoma is a rapidly increasing mass of blood flowing in between the coverings of the brain (Grubb and Coxe, 1978) resulting in increasing pressure on the surrounding areas. This initially results in compression of the air and liquid filled space around and within the brain, but gradually results in damage to brain tissue as it is pressed against the skull and eventually through the skull base.

Oedema, the collection of fluid in and surrounding brain tissue, results from either impact or increased intracerebral pressure due to damage to the tissue. The

consequent swelling within the bony cranium compounds the existing damage, including indirect damage, which results in further oedema and hence additional damage.

Loss of consciousness may immediately occur at the time of injury 'when the head accelerates freely and rapidly' (Gronwall and Sampson, 1974; Ommaya and Gennarelli, 1974) and is considered likely to be due to extreme stress, the resultant shearing, on the reticular formation structures (Grubb and Coxe, 1978). It has been shown that concussion indicates destruction of brain stem cells and fibres (Ommaya et al, 1973). When loss of consciousness is longer than twenty four hours, and occurs after an initially lucid period, this is the effect of raised intracranial pressure on the reticular formation. This normally indicates damage, as the result of pressure, to other brain structures and there is a clear relationship between raised intracranial pressure and poor outcome. The duration of loss of consciousness, and length of coma, can be used as an index of severity of damage, as it correlates highly with mortality (Heiskanan and Sipponen, 1970), psychosocial dependency (Najenson et al, 1974) and intellectual impairment (Levin et al, 1982; Levin, Grossman et al, 1979).

The lower brain stem structures are most vulnerable to the effects of swelling which may result in death if their activities are seriously affected. It is also a site strongly associated with severe disability in survivors (Broe, 1982). For these reasons, managing and controlling intracranial pressure is primary to the care of closed head injury patients, and high intracranial pressure is associated with death in such patients (Seitelberger and Jellinger, 1971). However, the relationship is not simple and there is controversy regarding the value of monitoring raised intracranial pressure in head injured patients

(Miller, 1985). A number of other physiological changes occur in the brain in response to brain injury, (Lishman, 1978) both ameliorative and destructive. A comprehensive account is given by Jennett & Teasdale (1981).

Accelerative Injuries

The rapid acceleration and deceleration of the head, occurring in motor vehicle accidents, is the most common cause of cranio-cerebral injury. Even in the absence of skull fracture, a wide variety of pathological lesions may result. These may be generalised (diffuse) lesions scattered throughout the brain, and may occur with or without localised damage, such as contusion, laceration and haemorrhage. There is clear neuro-pathological evidence to suggest that diffuse and non-specific damage is the predominant pattern (Adams et al, 1985; Jennett, 1986). Any focal effects are usually superimposed on more generalised damage. Diffuse axonal injury results from the shearing and straining of neurones, independent of any vascular or anoxic effects (Bigler, 1987; Adams et al, 1985). However, a diffuse, general picture is by no means the rule and clearly there is no simple relationship (Newcombe, 1982).

The nature of brain damage in closed head injury, particularly in accelerative injuries as caused in road traffic accidents, has a direct bearing on the cognitive and behavioural manifestations of the damage. This chapter will therefore finish with particular reference to, firstly, the role of accelerative injury in brain damage, and describe the involvement of the fronto-temporal region.

Damage due to accelerative injuries is considerably enhanced

by the further impact of the brain bouncing against the skull upon deceleration. The underside of the frontal and temporal lobes are particularly vulnerable to the impact of these forces (Ommaya et al, 1971; Walsh, 1978). The speed of impact in a moving vehicle further aggravates the shearing, stress and shock waves on the brain tissue, thus magnifying the fracture and severity of small lesions to nerve fibres and blood vessels. Ventricular enlargement is very common in severe closed head injury (Levin et al, 1981), is most likely to occur in patients experiencing prolonged coma following accidents involving moving vehicles, and is associated with poorer outcome.

Cerebral trauma, particularly following accelerative injuries, commonly involves bruising in the regions adjacent to the skull regions of the anterior fossa and middle cranial fossa, which forms the greatest brain-bone interface. As a result, the frontal and temporal lobes, being sited in the anterior fossa and middle cranial fossa respectively, are the areas most vulnerable to damage because of the peculiarities of the brainbone interface. This damage can occur regardless of the site or the direction of the initial impact (See Bigler, 1987 for a detailed description).

Because of the vulnerability of the frontal and temporal lobes to injury and their role in controlling intellect and cognition, it is not surprising that these are the most prominent sequelae of severe closed head injury.

The mechanisms involved in cerebral trauma are important for neuropsychologists as they help us to understand why some patients with closed head injury often demonstrate deficits suggesting localised damage, which may be distant from the actual area of impact (e.g. a 'frontal' picture including

disinhibition and poor planning). The evidence provided by detailed imaging techniques as well as careful neuropsychological assessment do not support a straight forward picture of diffuse damage and can provide valuable information which can be of use in planning a rehabilitation programme.

> 'The presence of residual neuropsychological deficits of memory and adaptive behaviour in many so called recovered patients, and the proven relationship between lesions of the frontal-temporal regions of the brain and these disorders, tempt one to draw a causal relationship between the major locus of damage in closed head injury and such deficits' (Walsh, 1985, p. 148)

The next chapter will discuss in detail the most common effects of severe closed head injury, particularly memory.

CHAPTER IV

The Effects of Severe Head Injury

CHAPTER 4

THE EFFECTS OF SEVERE HEAD INJURY

While some survivors of severe brain injury make a satisfactory recovery, others may be left with significant physical and mental problems which persist long-term. The underlying processes of recovery are not well understood, but it is largely agreed that early recovery is likely to depend on neural activity returning to systems which, although functionally disordered, remained largely intact. It is thought that late recovery may depend on the use of alternative neural pathways. While a degree of neurophysical deficit is common, this is not usually severe. Due to the widespread damage common after severe head injury, mental function is more likely to be affected than physical function. It is these mental deficits which are more likely to contribute to social disability than the physical sequelae (Jennett et al, 1981).

Physical Effects

Physical sequelae of closed head injury are generally considered to be uncommon, but may include motor system disorders, orthopaedic problems and sensory deficits. Post Traumatic Epilepsy is known to develop in approximately 5% of cases of closed head injury and can be profoundly disabling to young adults. It is considered to be the second greatest barrier, following organic psychological effects, to return to work (Jennett, 1975). However, perhaps surprisingly, even after very severe injury, physical disability is not usually of major importance. In McKinlay et al.'s study (1981) of very severely injured patients, 50

out of 55 patients were independently mobile by six months after injury and a further three managed with a stick or crutch leaving only 2 out of 55 who were confined to a wheelchair. However, whereas serious physical disability is uncommon, cognitive, behavioural and personality changes are much more common and are associated with stress in close relatives (McKinlay et al., 1981) and persisted at five years post-injury in Brooks et al.'s follow up (1986). Moreover these are also the problems which militate against return to work. In a further study, Brooks et al. (1987) followed up 98 patients between two and seven years after injury; 86% were employed before but only 20% after injury. The factors associated with a failure to return to work were cognitive, behavioural and personality changes.

Language problems, which may be significant during the initial phase of recovery from severe head injury, also are unlikely to persist longterm. Most patients do not demonstrate gross problems in language or praxis although subtle language deficits may also remain, usually characterized by word finding difficulty (Sarno, 1980). Constructional or praxis difficulties may be highlighted by tests of constructional or perceptual ability which also require memory, organisation or speed (Lezak, 1983). However, those deficits in language and praxis which do persist after severe head injury do not usually dominate the picture and are overshadowed by the more incapacitating defects in memory and attention.

INTELLECTUAL FUNCTIONING

Persistent intellectual problems have been reported to follow severe closed head injury. However, a recurrent finding is that general intelligence or IQ is not significantly impaired (e.g. Newcombe, 1982). For example,

even patients demonstrating significant long-term deficits in memory, attention and motivation, have been found to achieve score patterns on the Wechsler Adult Intelligence Scale which tend to approximate the average (McFie, 1976). Instead, intellectual impairment following severe head injury tends to be presented as an early stage effect, gradually improving over the initial months. Brooks and Aughton (1979), found that measures of intelligence showed marked recovery to at least a normal level during the first year following severe head injury, and only significantly differentiated severely head injured patients from controls at three months post-injury, and even then the difference was only evident on tests of non-verbal IQ. By 12 months post-injury, the only significant differences were in learning, memory and constructional skills, suggesting that their recovery is slower and poorer than intellectual or linguistic skills. The authors remark on the wide range of variation they found in both the extent and the pattern of recovery observed, and warn that:-

> 'recovery curves based on group data may mask wide individual differences in recovery, and these differences may be of great clinical significance if one is trying to predict outcome for an individual patient.'

Other studies have also shown variations when individual cases are compared, and a heterogeneous picture tends to emerge (e.g. Brooks, 1984). Indeed, Levin et al. (1979) report findings which contrast with the view that intellectual ability after severe closed head injury eventually recovers to a normal level. In a study of 27 patients whose Glasgow Coma Scale had been less than or equal to 8 on admission following head injury, the authors report that those patients defined as severely disabled (5/27) demonstrated marked intellectual deficits even at three years post-injury. In this group, no patient recovered to within two standard deviations of the

population mean. Levin and his colleagues also found that:-

'performance IQ particularly characterized long-term recovery from closed head injury as distinguished from Premorbid educational background'.

As shown in the previous chapter the most severely injured patients will suffer damage which is focal, fronto/temporal and diffuse, and therefore few patients with closed head injury will show only one pattern of impairment. The literature on head injuries amply demonstrates the presence of memory deficits at all degrees of severity and at all stages of recovery (Brooks, 1975; Brooks and Aughton, 1979; Schacter and Crovitz, 1977).

Both the nature and severity of the injury will have a bearing on the type and degree of the memory deficit. Memory problems may result from direct damage to the memory system, frontal lesions, diffuse damage or insult to the reticular formation and any combination of these (Jennett and Teasdale, 1981). Accordingly, the nature and presentation of the memory impairment can differ considerably between individual patients. The variety of functions considered to comprise memory are mediated by different structures and disrupted in different ways and therefore it is not surprising that their post-traumatic causes differ.

NEUROPSYCHOLOGICAL SEQUELAE

Research concerning neuropsychological recovery from closed head injury in adults indicates that cognitive impairment commonly persists after severe injury, despite improved motor function. But while there is a high probability of persisting memory deficits, this is not inevitable, even

after very severe injury (Newcombe and Artioli y Fortuny, 1979). Patterns of head injury vary in regard to the nature, severity and direction of impact and therefore there are no grounds for expecting a uniform pattern of cognitive impairment. However, it is reasonable to expect that diffuse, widespread brain damage often leads to permanent damage to some aspects of memory and learning. Clinical studies of the memory deficits following severe head injury have led to concern with related problems of attentional control. The importance of understanding the nature of the memory problem following severe head injury lies not only in its role in recovery processes and outcome prediction, but also in its impact on the patients day-to-day life, return to work and potential for rehabilitation.

THE NATURE OF THE MEMORY DEFICIT

The nature of the memory deficit which follows the acute period of post-traumatic amnesia has been discussed in a number of papers and chapters. Schachter and Crovitz (1977) provide a comprehensive review of the quantitative research, and Brooks' (1984) is also particularly valuable. On formal psychometric tests in general clinical use, forwards digit span is usually normal or near normal
but few other memory tasks are performed normally. Impairments on tests involving story recall, learning of paired associates and recall of visuo-spatial material are common. Considerable experimental and clinical evidence supports the view that the pattern of deficits reflects impaired long-term memory (Brooks, 1975). It is more difficult to say whether this deficit is caused by an impairment in registration, storage or recall, or to combinations of these, underlying impairment in registering

information, attention and mental tracking, immediate memory, learning and retrieval, or difficulty in assessing information without the benefit of cueing (Schacter and Crovitz, 1977).

Dikmen et al. (1987) studied 102 consecutive head injured patients at one and twelve months post-injury. Among other findings, the authors report that among those very severely injured patients performing significantly worse than controls at one year post-injury, performance varied according to the nature of the task presented. Deficits were more likely to be demonstrated by tasks requiring storage of new information into long-term memory, than by tasks which were either relatively easy, or which assessed certain processes such as orientation and long-term memory. That storage of new information is a significant and persisting deficit is supported by other studies (Brooks and Aughton, 1979) which have found learning of new information to be impaired long-term (Levin et al., 1979). Levin and his colleagues (1979) used the Bushke Selective Reminding Task to study a group of patients with 'severe' or 'very severe' head injuries. They found evidence of defective storage in some cases and of defective retrieval in others, and the authors concluded that there was marked heterogeneity in the nature of the memory impairment.

THE ROLE OF ATTENTION

In addition to memory deficits, other cognitive deficits may also be present, especially deficits in attention (VanZomeren et al, 1984). VanZomeren and his colleagues discuss in detail the nature of the attentional deficit in their review. There seems to be clear evidence for impairment of 'divided attention' following closed head injury. According to the authors, this refers to the need

for available processing capacity to be divided over several cognitive operations required for task performance. This impairment is also referred to as reduced speed of information processing. If this is reduced, it is then impossible to handle as much available information as usual and thus more information will be likely to go unnoticed. Even in patients described as making a 'good recovery' (Stuss et al., 1985), and who showed no obvious neurological or neuropsychological deficits at the time of referral, the ability to divide attention and memory under interference was the most significant impairment. The authors describe this as a capacity which is not measured by most tests and by day-to-day strictures, yet which appears to persist independently of recovery time. Related to attentional control is the ability to process information.

Gronwall and Wrightson (1981) studied the relationship between post-traumatic amnesia, memory test performance and performance on the Paced Auditory Serial Addition Test in two samples of closed head injury patients. They found an attention and concentrational factor, related to PASAT scores, to be significantly related to post-traumatic amnesia. The authors also found a deficit in the patients' ability to place information into long-term memory storage, which was also related to length of post-traumatic amnesia. A third finding of interest was that patients demonstrated impaired ability to retrieve information once it was stored, and this was not predicted by either length of post-traumatic amnesia nor by PASAT scores. It has also been suggested (VanZomeren et al, 1984) that impaired attentional processes may lead to failure to attend to the material to be remembered, preventing adequate storage.

RECOVERY OF COGNITIVE FUNCTION

The relationship between the degree of memory impairment and the severity of the injury, as measured by the duration of post-traumatic amnesia, has been clearly demonstrated in several studies (e.g. Brooks, 1972, 1984). Dikmen et al. (1987) found that head injury severity indices were more closely related to early behavioural outcome than late outcome, and that at one year post-injury only the very severely injured patients (with post-traumatic amnesia greater than two weeks) performed significantly worse than controls on a variety of cognitive tasks.

The nature of the damage is also a factor, with diffuse damage being a stronger predictor of persisting problems in memory than focal damage (Brooks et al., 1980). The process of recovery appears to be influenced by the underlying cause of the memory deficit. Thus, those activities which have a large attentional component, such as immediate attention span, tend to improve quickly and reach a plateau within the first six months to a year after injury (Gronwall and Sampson, 1974; Lezak, 1978). Activities such as new learning that involve the memory system tend to improve over a longer period of time (Lezak, 1979). Deficits having to do with retrieval, rather than registration and learning, tend to improve as specific verbal and visuospatial functions return. However, when the ability to engage in retrieval is sluggish, due to frontal and subcortical damage, only minimal improvement may occur, following soon after the return to consciousness (Lezak, 1979).

In summary, it appears that there is a high probability of persisting memory deficit after severe head injury, although this is not inevitable even after very severe head injury (Newcombe and Artiolo i Fortuny, 1979). General

intellectual ability is likely to be relatively intact or at least less impaired, even in the presence of profound memory deficit, but gross deficits in language and praxis are unlikely to be present beyond the early stages of recovery. The pattern of the head injury itself may vary according to the nature, source and direction of impact, so there are no grounds for expecting uniform patterns of cognitive impairment. Permanent damage to areas of memory and learning, particularly due to impaired ability to process and store new information, appears to be most closely related to severity as measured by length of post-traumatic amnesia, nature of damage, i.e. diffuse rather than focal, and time post-injury.

PSYCHOSOCIAL SEQUELAE

Emotional Problems

Cognitive deficits following severe head injury have been found to improve over time and the pattern of recovery is related to severity of injury. Emotional recovery may improve correspondingly, but there is evidence to suggest that in some cases emotional function may worsen over time (McKinlay and Brooks, 1984; Brooks et al., 1987).

Fordyce et al. (1983) examined the emotional characteristics of head injury patients as a function of time post-injury. They found that patients referred six months post-injury were more emotionally distressed than an acute group, tested six months post-injury or earlier. The more chronic group were found to be more anxious and depressed, more confused in their thinking and more socially withdrawn. Interestingly, emotional functioning appeared unrelated to the level of neuropsychological impairment. The authors

suggest that enhanced emotional distress related to increased awareness of impaired functioning as time passes. The role of insight in emotional recovery has been cited in a number of studies (Lezak, 1978; Tyerman and Humphrey, 1984), suggesting that as the acute stage of relatively rapid cognitive and physical recovery ends, patients become aware of the possibility of long-term residual deficits. In the absence of rehabilitation aimed at helping patients cope, and at least adapt to their problems, they may in fact deteriorate emotionally and behaviourally (McKinlay et al., 1981).

Fordyce et al.'s findings suggest that pre-morbid characteristics of poor impulse control and personality dysfunction may not only contribute to later problems with emotional adjustment, but when also present with increased awareness of residual neuropsychological deficits, may lead to heightened emotional distress. The authors emphasise the need for rehabilitation efforts to take these problems into account.

Brooks et al. (1986) examined the psychological sequelae of severe head injury for considerably longer (up to five years post-injury) and in more detail, identifying specific problems. The authors also used close relatives of patients as a source of information. They had previously found that at one year post-injury, the emotional and behavioural disturbances placed a greater burden on the relatives (McKinlay et al. 1981). In the 1986 study, they found that at five year follow-up, the report of continuing personality change had increased from 60% to 74% and over all occasions was the most frequently reported problem. While a number of relatives reported persisting problems involving slowness, memory, irritability and bad temper, threats of violence had increased dramatically from 15% to 54%. The situation of

the relatives deteriorated markedly, as indicated by the relatives' increase in subjective burden scores, a measure of strain and distress experienced by the relative as arising from objective changes in the patient.

That stress on relatives of head injured patients is significant and persisting has also been highlighted by Oddy et al. (1978) whose group had less severe injuries than in the Brooks et al study. The authors found the time of greatest stress to be in the month following injury, and that this declined and levelled off at approximately six months post-injury. Stress did not appear to diminish after this point, being unchanged at twelve months. As in the previous study, stress appeared to be mediated by the relative's perception of personality changes and subjective deficits, and was not related to head injury severity and associated disabilities. Instead, the nature of the relative's distress was related to the stress of behavioural and physical problems relating to the head injury and also to concern regarding the patients further recovery and vulnerability. The authors suggest that relatives need to be given an estimate of the future course of personality changes.

Psychosocial Recovery

While the severity of head injury is directly related to persisting cognitive deficits, the relationship with psychosocial adjustment appears to be more complex. While some studies have found that the severity of the injury makes behavioural problems more likely, others have suggested that significant psychosocial and behavioural problems may persist even after relatively mild injuries (Rimel et al., 1981).

In a follow-up study of 50 severely head injured patients and their families, Thomson (1974) found that the majority suffered from lack of social contact and almost all the families complained of personality and behaviour changes. Again, cognitive sequelae rather than physical deficits put the greatest burden on relatives. Personality problems were reported as the most difficult to cope with, the most common being irritability (rather than temper), spontaneity, restlessness, emotional regression and stubbornness. Interestingly, patients made few spontaneous complaints and appeared to be more aware of memory problems than of behavioural changes. Overall, the main problem appeared to be lack of social contact and loneliness.

The term 'psychosocial' encompasses a wide range of psychological, emotional and behavioural effects of head injury, whose aetiology is complex and is likely to be related to pre-morbid factors. These may include pre-existing personality traits, including impulsiveness and ability to cope with stress (Fahy et al., 1967; McKinlay and Brooks, 1984; Bond, 1983).

Standard measures of neurological outcome and self-care may suggest that the individual has made a 'good recovery', yet these studies show that the subjective reports by patients and close relatives may indicate significant problems. Thus, sensitive measurements are needed to determine the extent to which psychosocial problems continue to disable the patient.

Behavioural Problems

Recent research indicates that behavioural disturbance makes a major contribution to disability after head injury, playing an equal or greater role in overall outcome than

motor or cognitive deficits (e.g. Fordyce et al., 1983). A range of problematic behaviours may occur, which can depend on severity of injury, the stage of the recovery process, pre-morbid adjustment and the post-injury environment (Levin, 1982; Lishman, 1973).

After the early stages of recovery, the acute features of agitation, post traumatic amnesia and the affect disturbance largely settle down. However, modifications of these may remain, presenting as aggressiveness, irritability and a mood disorder, often together with poor memory (McKinlay et al., 1981). Temper problems are frequently reported in the literature which may present in a range of severity, from irritability over trivial annoyances to severe physical violence (Brooks and McKinlay, 1983; Thompson, 1987). Brooks and McKinlay found that acts of aggression not only persist long-term, but may actually increase in severity. Together with poor memory, aggressive behaviour tends to be a major contribution to the stress experienced by relatives (Brooks and McKinlay, 1983).

The frequency of reported aggression, to varying degrees, is well documented in studies of social adjustment following severe head injury (Livingstone et al., 1985). It does not appear to occur in isolation, however, but together with related problems, such as physical or cognitive deficits, and is often associated with other indicators of poor overall social adjustment, such as social isolation. Newton and Johnson (1985) depict the patient with severe head injury as 'lonely, anxious, poorly adjusted, with poor social skills and experiencing frustrations', as measured on the Katz Adjustment Scale.

It appears that the absence of social contacts cannot be attributed to physical status (Weddell et al., 1980), but

that poor cognitive ability is important, leaving the patient feeling socially inept (Oddy and Humphrey, 1980). In general, patients do not appear content with their situation (Tyerman and Humphrey, 1984).

In view of this, it seems likely that low self-esteem and a poor sense of self-efficiency may contribute to the persistence of the problems long-term, and that rehabilitation efforts aimed at increasing the patient's sense of control would be appropriate. Fordyce et al. (1983) found emotional distress, as indicated by clinical levels of anxiety and depression, to be influenced by the passage of time since the injury. They suggest that with time, the patient's insight or awareness of the persistence of their deficits, confused thinking and social isolation appeared to worsen. They suggest that increased awareness, together with what may be previously marginal coping skills, may aggravate poor adjustment even further. It has also been suggested that self-awareness, in the absence of insight, can lead to paranoia (Lezak, 1978).

The Role of Insight

The role of insight thus appears to have an important bearing on psychosocial recovery. While increased awareness may have a negative influence on mood, it may enhance its importance in that potential for the patient to respond to rehabilitation may be considerable. Tyerman and Humphrey (1984) examined 25 patients with severe head injury whose mean time post-injury was seven months. They investigated the changes in self-concept using a variety of scales. As in other studies, anxiety and depression were found to be common. They also found that the patient's self-concepts changed considerably over time, yet despite this, they anticipated returning to their pre-morbid selves within a

year, despite expressing an idealized view of their past selves. The authors conclude that while unrealistic expectations may protect the patient in the early stages, even possibly providing some motivation towards recovery, if present in the long-term would hinder both rehabilitation and adjustment. The authors view lack of insight as a stage in recovery which precedes adjustment.

Viewed in this light, lack of insight would appear to be an obstacle which needs to be overcome in order for rehabilitation to be effective, as its persistence may compound other problems (Lezak, 1978). A comprehensive study of deficit awareness and treatment performance in 45 severely head injured adults carried out by Lam et al. (1988), provides qualified support for the idea that head injured patients with awareness respond better to treatment. The authors used a Change Adjustment Questionnaire to assess the patients' stage of change and to determine a 'treatment matching' strategy. For example, patients who were unaware of their deficits (pre-contemplation stage) would not be expected to benefit most from treatment which focused on taking action. Instead, they suggest, it would be more valuable at this stage to gear treatment to helping the patient recognise their problems. Conversely, patients who were fully aware of their deficits would be more frustrated by such a treatment approach and would be better targeted towards active participation in treatment. The role of counselling in increasing self-awareness can also aid the patient's families in re-adjusting their expectations of the patient (Lezak, 1978). More recently, rehabilitation efforts have been developed which specifically aim to increase insight following brain damage (Prigatano, 1986).

The Family Response

It has been suggested that in the early stages of recovery family life and marital relationships appear to be able to withstand the changes following severe head injury (Oddy and Humphrey, 1978). However, some studies have found that family life is among the most disrupted areas of life (Bond 1975, Bond and Brooks, 1976). Lezak (1978) has described in detail the way in which brain injury, which results in character change, can disrupt family interaction patterns, which can create problems in adjustment for the patient's close family. She considered caretaking spouses and dependent children to be particularly vulnerable to emotional stresses and that even female spouses with stable marriages and personalities can feel like they are 'going crazy', due to the strain of combating frustration, disappointment, fatigue and depression. While she found that virtually all family members experience some degree of depression, this could be aggravated by unrealistic expectations regarding the time course and degree of the patient's recovery. In addition, it is often the inability to adapt intact knowledge to everyday situations which leads patients, even with reasonable motor and intellectual abilities, to behave in a childish, dependent manner, leaving decision making and control over impulses to the relatives.

Family expectations for full recovery play a significant role in their efforts to keep the patient in the early stages of recovery. External factors may enhance these expectations to an unrealistic degree. For example, if recovery is based on sensory and motor aspects of improvement, the relative and patient may be led to expect a parallel recovery in cognitive and behavioural functioning. In addition, relatively rapid early improvement will

encourage such hopes in relatives who expect day-to-day gains to continue long-term. In addition, the patient's familiar appearance and behaviour patterns can make more profound and subtle changes difficult to appreciate and accept. As a result, family members may respond to the patient as they remembered him/her, rather than to the altered person. Lezak (1986) suggests that it may take many months before the family are able to adjust to, and accept, a more realistic view of the patient.

This process is perhaps best understood as occurring in a series of stages, comparable to that experienced in other areas of grief (Kubler-Ross, 1969). While the order and rate of passage through these stages may vary, a fairly consistent constellation of features appear to occur.

Early Stages

Relatives appear largely to be able to remain optimistic and motivated in the initial period of recovery. Focusing on physical features of disability and recovery can enable relatives to play down the significance of emotional and behavioural changes, attributing these to frustration and excitement. Gradually, this optimism may begin to fade and anxieties regarding the patient's persisting difficulties arise. Brooks and McKinlay (1983) found that relatives become increasingly aware of, and burdened by, the patient's difficult behaviour over the first year. During these early stages, the relatives are not ready to accept that changes in the patient are likely to be permanent. Initially, even advice based on realistic expectations may be rejected and would be inappropriate if given. Once the persistence of the difficulties is more apparent, however, advice may be geared at helping them become more objective about the patient's deficits and the possibility of a less than

complete recovery.

Middle Stages

As the patient recovers physically, the persistence of disruptive and inappropriate behaviours becomes more obvious. Poor judgement in the patient may become apparent by the contrast between the patient's inability to carry out day-to-day tasks, and the expressed wish to resume pre-morbid activities. Relatives at this stage may become more aware of their own subjective stress and the effect of this on their interpersonal relationships. Lezak et al. (1980) found that family members reported these effects with increasing frequency over time, to the extent that 81% reported a deterioration in interpersonal relationships by the second year. Brooks and McKinlay (1983) found that families were more likely to report personality changes at six and twelve months than at three months and other studies tend to support this view (e.g. Rosenbaum and Najenson, 1976). As full awareness of the degree and persistence of the patient's deficits develops, the relative will normally become more able to request and accept help aimed at realistic approaches to modify difficult behaviour and to learn compensatory strategies for cognitive deficits.

Later Stages

As in other areas of grief work, a period of genuine sadness and mourning appears to be a requisite for coming to terms with permanent disability. Increased insight and emotional objectivity can allow relatives to 're-orientate' themselves regarding role changes and adjustments, as well as reinterpreting their relationship with the patient. Lezak (1978) cites the example of an elderly wife who, by looking at herself as a hired housekeeper, with no emotional ties to

the patient, was able to look after her 'self-absorbed and irascible' husband with minimal emotional pain. The psychologist's role at this late stage may be most appropriate in gearing the family towards long-term, community resources and by counselling regarding separation or divorce.

In summary, the family's response to the sequelae of severe head injury depends on a number of factors including time since injury, their own personality adjustment, the nature and quality of their relationship with the patient and their tendency towards denial or insight. It seems that emotional distress may run an uneven course and that low mood and increased stress may in the later, rather than earlier stages, play an important role in more positive aspects of adjustment, such as increased insight. By carefully aiming psychological intervention to match the particular stage and needs of the family, progress towards resolution and acceptance can be facilitated. Family counselling may best be continued even after interventions directly aimed at the patient have ended, as marital and divorce counselling may only be appropriate when all rehabilitation efforts have been exhausted.

Rehabilitation of Psychosocial and Behavioural Problems

The previous studies show that emotional and behavioural sequelae are, in addition to the cognitive sequelae, significant factors in the stress experienced by severely head injured patients and their caregivers. Rehabilitation efforts directed towards these are wide ranging and are continuing to be developed. As the main emphasis of the present study is on memory rehabilitation, psychosocial rehabilitation will not be detailed here. However, a few studies are relevant to a family based approach to day to

day memory problems, as an ecologically based treatment will involve patients interacting in social situations where behavioural deficits are potential barriers even to the success of the memory rehabilitation itself.

Approaches to the psychosocial problems encountered following severe head injury range from methods aimed at behavioural excesses, particularly aggression and disinhibition (Eames and Wood, 1985) which prevent rehabilitation or care in ordinary settings, to programmes aimed at improving interpersonal skills (Braunling-McMorrow et al., 1986). While the first approach is now widely used in in-patient rehabilitation settings, the latter is more commonly introduced once the patient is being reintegrated to the community. Frequently, methods aimed at improving cognitive skills overlap with those aimed at improving social skills (Carberry and Burd, 1987; Yvlisaker,1987) in view of the way in which deficits in these areas interact and are often difficult to disentangle (Prigatano, 1986). Recent approaches are inclining towards a cognitive behavioural model (e.g. Alterman and Burgess, 1990).

The potential value of the role of the family in such treatments has been acknowledged frequently (Rogers and Kreutzer, 1984; Anderson and Parenté, 1984; Ben-Yishay, 1981, 1982, 1983) but is rarely implemented. Yet, involvement of the family in the treatment of psychosocial deficits would seem a practical means of aiding generalization of appropriate behaviours to real life settings. In addition, it may also highlight family interactions which may be hindering patients' social skills, for example, by over-protectiveness. Social skills training is relevant to a programme involving remediation of everyday memory problems, which aims to achieve generalization of treatment effectiveness in real-life settings. Equally

important, the role of the relative in helping the patient to maintain generalization after treatment ends would seem a meaningful measure of both memory and social skills training.

CHAPTER V

Memory Rehabilitation

CHAPTER 5

MEMORY REHABILITATION

Measurement and identification of real-life memory problems following brain injury have been the focus of discussion and debate by neurpsychologists over recent years. In particular, it is often reported that a discrepency exists between the patient's performance on formal psychometric tests and his/her subjective report of everyday forgetting (Newcombe and Artiola i Fortuny, 1979). Formal tests enable us to measure changes in the patient's performance on highly structured and specific tasks and may be a sensitive way of detecting change or analysing the nature of the deficit (Newcombe and Artiola i Fortuny, 1979). However, their lack of relevance to day to day memory reduces their clinical significance (Sunderland, Harris and Baddeley, 1983). Efforts to develop more environmentally relevant assessment methods, such as the Rivermead Behavioural Memory Test (Wilson, Cockburn and Baddeley, 1985) provide a promising alternative in attempting to bridge the gap between laboratory and real-life performance and further development of such tests is needed. Such alternatives are scarce, however, and in the main, current neuropsychological assessment lacks such ecological significance, leaving us with the practical question of whether any advice can be given to the patient who report difficulty in day to day memory.

Cognitive rehabilitation strategies are becoming increasingly directed to the everyday problems (Wilson, 1987; McKinlay and Hickox, 1988) and highlight the importance to the clinician of having a means of obtaining a

clear picture of the patient's experience of everyday memory. This could then be used as a basis from which appropriate rehabilitation and mnemonic strategies can be devised and evaluated. The need for remediation efforts to be aimed at these day to day memory failings is particularly apparent in patients with closed head injuries. Not only do they show persistent deficits on formal psychometric tests (Brooks et al, 1987; Levin et al 1979) but memory is also found to be a significant and persisting problem in the everyday setting, placing the greatest burden on relatives (Brooks et al, 1986), and is a key factor in return to work (Brooks et al, 1987). However, only recently have researchers addressed the task of developing an ecologically valid means of identifying the everyday memory problems of patients (Broadbent et al, 1982; Sunderland, Harris and Baddeley, 1983).

The previous chapter detailed studies which provide ample evidence that residual memory deficits are among the most frequently reported sequelae of severe closed head injury in adults (Brooks, 1984; Kapur and Pearson, 1983; Van Zomeren and van Den Burg, 1985). The complexity of memory functioning and the interrelationship between memory and other cognitive processes determine that the behavioural characteristics of a specific memory problem be clearly outlined from the beginning of any memory rehabilitation programme. An understanding of the multiple aspects of memory, together with those factors which influence learning, can help an analysis of the memory problem and to define the focus of treatment.

Current head injury rehabilitation literature (e.g Wilson and Moffat, 1992; Wilson, 1987) gives particular attention to two approaches to the management of memory disorders. These are 1) direct retraining, including repetitive recall

drills and 2) mnemonic strategy training and compensatory methods.

Direct Retraining

Direct retraining refers to techniques which aim to improve memory functioning through the use of repetitive memory exercises. This usually includes list-learning or story recall tasks (Landauer and Bjork, 1978). Methods have also included computer-administered memory laden tasks (e.g. Gianatsos and Gianatsos, 1979), the practice of visual imagery (Patten, 1972; Wilson, 1982) and the use of peg methods (Moffat, 1992). This drill approach to learning, although widely practiced, has had disappointing results (Wilson and Moffat, 1992). Research has recently shed doubt on the practice of improving a complex cognitive process such as memory simply through exercise (the 'mental muscle building' model of rehabilitation) (Harris, 1984; Harris and Sunderland, 1981). While in some cases patients have improved their performance on a specific set of items, this has not been shown to generalize to any other task, particularly outside of the laboratory setting. It has even been suggested that such muscle building techniques are the least effective for helping brain injured patients remember material (Cermack, 1975). The limited success of these techniques is not surprising in view of their contrast with 'real-life' methods. Harris (1980) found in interview studies, which included both University students and homemakers, that the most popular techniques were external aids, such as lists or diaries. Nor do they neccessarily relate to the 'real-life' memory failures experienced by head injured patients. Sunderland and his colleagues (Sunderland, Harris and Baddeley, 1983; Sunderland, Harris and Gleave, 1984) found that the most common complaints include absent-mindedness, failure to pass

on messages, and failure to remember the sequence and details of recent events.

It may be argued in favour of such techniques, however, that they may help to build morale in patients with stable residual deficits, when they believe they are doing something to 'improve their memory' (Harris and Sunderland, 1981). They may also have the effect of increasing the patient's awareness of memory problems and encourage him/her to try compensatory strategies. It has also been considered that just as early physical exercise may have a beneficial effect in brain damaged animals, so might memory exercise somehow enhance recovery during the early, critical period of neural regeneration (Harris and Sunderland, 1981).

While repetitive exercise does not appear to improve the overall efficiency of memory or learning, extensive repetition may be needed to enable amnesics to store new information into long term memory (Wood, Ebert and Kinsbourne, 1982).

'Even in the case of severely amnesic patients, conditioning and procedure learning are possible when they are given an adequate number of trials' (Baddeley, 1982).

Such patients have been able to learn facts and procedures through practice, yet have no recollection of the practice. This has also been found in severely head injured patients acquiring orientation information when rehearsed daily (Ylvisaker et al, 1987). However, this is not evidence that the memory functioning of the patients has improved, nor is it a convincing argument that this is a valid use of the patient's time (Wilson, 1990).

Compensation

This involves the deliberate use of internal memory strategies (Mnemonics) and external memory aids. The use of

mnemonics (e.g. creative associations, visual images and acronyms) has been found to have value in the treatment of specific memory problems, such as forgetting people's names or the location of places or objects. (Moffat, 1992; Wilson, 1987).

Mnemonic Strategy Training

This involves improving cognitive processes or systems related to memory. This more general approach has been found productive. Implicit in this approach is the assumption that amnesic patients and their non-impaired counterparts may benefit from deeper semantic processing by making the material to be remembered more distinctive, either by organisation or association. While this does not imply that the memory problem was due to shallow semantic processing, it does indicate that amnesic patients can improve learning when the means of processing information is modified or enhanced. A good example of this is the PQRST technique, which has been studied using both normal and brain injured populations (Glasgow et al, 1977; Wilson, 1987; Koning-Haanstra et al, 1990).

While severe head injuries may result in various deficits that do not resolve completely, it does appear that certain basic level cognitive processes may be improved with intense and well targeted exercises (Ben-Yishay et al, 1982). However, full restoration of function is, in most cases, not a realistic expectation even with the most intensive direct retraining.

Indirect Training

When intractable deficits interfere with the attainment of desirable goals, it may be more constructive and realistic

to provide compensatory strategies. These may be environmental compensations, for example, reducing expectations of others for the patient's performance and providing environmental cues and support to enable the patient to complete a given task, or they may be compensatory strategies, which the patient uses deliberately to achieve a goal, e.g. external memory aids. Most of us use a combination of both external aids (to enhance our orientation and memory) as well as internal procedures (e.g. self-instruction, mental organization of information, rehearsal of responses). As patients with brain injury are usually more limited in their ability to process information unaided than those without brain injury, they may need more strategies and to apply these more systematically in order to cope with everyday demands on memory.

Patients themselves may select compensatory strategies which may be escapist, e.g. avoiding the situation, or inefficient, e.g. trying to use complex mnemonics when a simple written reminder may be more useful. Most importantly, however, compensatory strategies hold greater promise of success than direct retraining of impaired cognitive functions (Prigatano et al, 1986). Especially as diffuse bilateral damage is a hallmark of severe closed head injury 'a carefully designed program of strategy training is thus unwarranted for many adults in the late stages of recovery from severe head injury' (Ylvisaker et al, 1987). Ylvisaker et al suggest several factors to be considered in selecting candidates for teaching compensatory strategies. These are detailed here, as they appear to integrate knowledge based on the studies of both cognitive functioning and of memory rehabilitation after severe head injury, and thus may offer valuable indicators for the present study. These factors include:

1. General cognitive level: the patient should be oriented and not show a severely depressed cognitive profile.

2. Working memory: the patient needs sufficient attentional resources to think both about the task at hand and a compensatory procedure that would aid performance.

3. Awareness of deficits: if the patient is going through the motions but is not really engaged in the process, treatment may need to focus on self-awareness of strengths and weaknesses.

4. Metacognitive level and 'executive' functions: the patient needs to be able to think abstractly about attending, learning, etc.

5. Goals: these must not be unrealistic or absent. The therapist can help the patient form provisional goals.

6. Environmental support: the active support of significant others will be needed.

7. The range of applicability of the strategy. Much of the literature on mnemonics focusses on strategies with little practical value (Wilson and Moffat, 1992).

8. Difficulty or unwillingness to use strategies which are complex or time consuming.

Other factors to be considered are:

1. Concreteness of the strategy: concrete methods may be more useful than abstract, unless the patient is returning to a complex job or university.

2. Knowledge presupposed by the strategy, for example, categorizing.

3. Definable neuropsychological strengths and weaknesses the strategy should capitalize on the patient's strengths.

4. Metacognitive demands of the strategy: external aids require less than internal procedures.

Generalization

There is little documentation of the efficacy of strategy intervention with head injured patients, and measures of longterm treatment gains or generalisation of strategies to other settings are scarce (see Levin, Benton and Grossman, 1982, for a review). However, from the previous studies, it seems likely that 'laboratory bound' treatments for patients who may have significant learning impairments would be expected to have limited, if any, efficacy outside the learning setting, particularly if strategies are not aimed at meaningful, real-life problems experienced by the patient. Ylvisaker et al's guidelines above are therefore welcome indicators in a what is still a relatively unchartered area of research.

In order to achieve generalization, rehabilitation efforts would seem to be best directed to the types of everyday memory failures reported by head injured patients (Sunderland, Harris and Baddeley, 1983). These could not only provide a target to which strategies could be aimed, but also provide ample opportunity for practice (Hickox and Sunderland, In Press). In addition, environmental support which involves the help of significant others would seem an obvious opportunity which has so far been largely overlooked in memory remediation studies.

FAMILY BASED REHABILITATION

The studies discussed in the previous chapter have shown that the head injured patient does not experience his/her problems in isolation and that relatives bear a considerable burden from caring for head-injured patients. Not only do they experience emotional stress and role changes, but their own attitudes may influence the patient's recovery process (McKinlay et al, 1981; Oddy & Humphrey, 1980). It seems reasonable, therefore, to suppose that relatives who share the patient's day to day environment might also have a potential role in ameliorating the problems faced by the patient, and that a comprehensive rehabilitation plan will not only focus on the patient's specific cognitive and behavioural problems, but should involve the relative in planning and carrying out of treatment goals.

A number of recent studies have looked at the potential role of relatives in rehabilitation of head-injured patients. Livingstone (1986) found that, despite persisting deficits in behaviour and psychological functioning up to one year post-injury, there was a very low uptake of rehabilitation services by the families. Livingstone considered that the tendency for clinics to offer a piecemeal approach, i.e. with a focus on physical aspects of head injury, left the more persistent and burdensome psychological deficits unattended. He stresses the need for a coordinated approach to rehabilitation for patients and their relatives. Panting and Merry (1972) also emphasise the need for a coordinated approach to psychological problems following severe head injury, with particular attention to the need for family support.

Rogers & Kreutzer (1984) describe the crisis in families which can arise as a result of head injury. These include

problems in family adjustment, such as dramatic role changes, financial burden and social isolation. Unless the family receives constructive direction, they may not be able to help themselves or the patient. Rogers & Kreutzer describe their approach of 'social networking' which systematically organises and strengthens the family support system. This involves gathering the patient's family, friends and acquaintances in the community to be educated regarding the effects of head injury and possible outcome. Then, sessions involve the participants in a discussion of potential problems and their solutions. It is a goal oriented approach, which if successful, trains participants to eventually cope independently without professionals. While the logistics of networking may pose a number of practical problems, such as scheduling and differing levels of motivation between members, it does appear that by sharing the planning and responsibility of treatment, the family can re-adjust its expectations and find practical strategies to help the patient.

A more concise method of family-based rehabilitation has been described by Anderson and Parentẽ (1985) who consider that outpatient cognitive rehabilitation is best offered as a family therapy process, with family members acting as therapy assistants. They describe a number of specific exercises in Attention, Organisation, Verbal Mediation/Mnemonics and Imagery which families are taught to use at home. The strategies are simple and easy to teach to non-professionals and transfer readily to day-to-day activities.

Such an approach, focussing on practical help which families can give to the patient, may be expected to reduce the sense of helplessness experienced by families and increase feelings of self-worth, as well as providing the patient

with more opportunity to benefit from remediation than merely attendance to an out-patient clinic would allow. The patient is therefore more likely to achieve generalisation by the frequent practise of realistically aimed techniques.

Such a practical approach does not, however, address the emotional problems experienced by relatives which may need to be tackled before the relative feels able or willing to offer such help. Denial, resentment, anxiety and depression resulting from unresolved feelings about the patient's injury may result in non-compliance, which may impede and sabotage the treatment process (Romano, 1974). When this happens, the most appropriate approach would seem to be one geared to helping to resolve these issues, and clearly a comprehensive rehabilitation would be a flexible one.

Following on from these considerations, the present study has four elements considered to be of key importance.

1. The memory strategies used should be simple and not themselves impose any more burden than necessary on the patient's limited information processing capacity (see VanZomeren, Brouer and Deelman, 1984). This should make it easier for patients to find methods acceptable.

2. In view of the problems of patients forgetting to use mnemonics and aids (Gloag, 1985), the help of relatives acting as co-therapists, will be used to try to achieve overlearning and generalisation.

3. Clear documentation and homework assignments will be available to back up training sessions and remind patients and relatives of what they are to do.

4. In view of the lack of real-life prediction available

from tests and the evidence that patients' retrospective questionnaires are not valid (Sunderland, Harris and Baddeley, 1983), the main outcome measures will be checklists of 'real-life' memory failures completed at the time by patients and, when feasible, relatives.

CHAPTER VI

The Present Study

CHAPTER 6

THE PRESENT STUDY

THE AIM OF THE PRESENT STUDY

The aim of the present study is to provide answers to the following questions, in the context of training individuals with severe head injuries on an out-patient basis, with the active involvement of close relatives.

1) Do memory aids and/or mnemonics, or a combination lead to a reduction in day-to-day memory difficulties?

2) What effect does treatment have on the psychological well-being of the patient and relative?

3) Can relatives be trained to act as co-therapists to help achieve generalisation in real-life environments?

4) Are there features of patient and relative which are associated with favourable outcome to treatment?

The variables considered include severity of injury, time since injury, demographic features and the role of insight in determining willingness to work towards intermediate goals and accept less than an idealized outcome. It is expected that only tentative answers to this last question are possible, in view of the nature of the study.

DESIGN OF THE PRESENT STUDY

In order to find answers to the preceding questions, the

present study uses a multiple baseline design in order to evaluate the effectiveness of simple mnemonic strategies taught to severely head injured adult out-patients. Relatives are closely involved as co-therapists. In view of the lack of real-life prediction available from tests and the evidence that patients' retrospective questionnaires are not valid (Sunderland et al, 1983), the main outcome measures are checklists of 'real-life' memory failures. Clinical psychometric assessments of intelligence, memory and concentration are included, as are the questionnaires regarding the patients memory failures. In addition, self-ratings of mood and subjective burden are used in order to assess the well-being of both patients and relatives.

Subjects

Ten severely head injured patients referred by head injury out-patient departments in Lothian Region served as experimental subjects in this study.

Criteria for Inclusion

The following criteria were applied:

1. Subjects were adults (male and female) aged between 16 and 60 years old.

2. They sustained a severe closed head injury. 'Severe' is defined as at least two days of post-traumatic amnesia (PTA) following Russell's (1971) terminology.

3. Patients were referred to the study from head injury follow-up clinics or rehabilitation follow-up clinics in the Lothian Region.

4. Subjects reported experiencing day to day memory problems.

5. A close relative or significant other person was available to participate actively in all stages of treatment.

6. Consent to partake in the study was granted by the patient and relative after information regarding the purpose of the study and the details of the assessments and treatment were explained fully.

7. In order to obtain subjects with reasonable prospects for success, the following exclusion criteria were applied:

   a) pre-existing neurological impairment.

   b) history of psychiatric disorder

   c) history of drug abuse

   d) history of dependence on alcohol

   e) severe communication difficulties

The study was approved by the relevant ethical committees.

The regulations of the Data Protection Act were fully complied with.

METHOD

Design

A multiple baseline across subjects design was employed. this single-case method has been found to be particularly valuable in head injury rehabilitation (e.g. Wilson, 1987; Koning-Haanstra et al, 1990), as it allows for the possibility of an improving baseline and an irreversible intervention effect. This design allows improvements due to factors unrelated to treatment, e.g. practice or recovery, to be separated out. In addition, it does not require treatment to be withdrawn.

The baseline period consisted of assessments and observations of the problem behaviour without intervention. In order that the treatment to be used could be evaluated, a stable baseline was to be obtained so that the naturally occurring range of frequency of the problem could be established. The baseline phase was followed by a treatment phase. In a multiple baseline across subjects design, the intervention is introduced after a baseline of varying length, in this case 4, 5, 6, 7 or 8 weeks. This is the independent measure. If the treatment is effective, improvements will occur after treatment begins. The main dependent measure used was a Memory Checklist of everyday memory failures which patient and/or relative completed daily.

The study consisted of the following stages.

1. Referral from clinic
2. Check inclusion/exclusion criteria
3. Initial assessment
4. Baseline period

5. Second assessment, prior to treatment
6. Treatment phase
7. Post-treatment phase
8. Follow-up assessment

Stages 1 & 2 have been described already. The assessments at stages 3, 5, 7 & 8 consisted of separate interviews with the patient and a close relative or main carer and a neuropsychological examination.

MATERIALS

I. Interview

The interviews with patients were based on a semi-structured interview schedule and self-administered checklists derived from the works of McKinlay et al (1981) and Brooks et al (1986). This provided an assessment of 1) the patient's self-report on changes resulting from the injury, 2) the relative's view of how the patient has changed in physical, cognitive, emotional and behavioural terms and 3) the degree of stress experienced by the relative. A copy of the interview schedule can be seen in the Appendix.

II) Memory Questionnaires

Cognitive Failures Questionnaire (Broadbent et al, 1982)

This questionnaire consists of 25 questions about the frequency with which the respondent has made mistakes over the preceding six month period. Items cover everyday errors in perception, memory and motor function. The CFQ for others was presented to relatives and is designed to identify those aspects of cognitive failure apparent to

others.

The Everyday Memory Questionnaire (Sunderland, Harris and Baddeley, 1983). This is a 16 item self-report questionnaire which indicates the frequency of memory failures which occur commonly after head injury. Both patient's and relative's versions were administered.

Memory Checklists

This is a list devised for this study, comprising 14 memory problems drawn from those commonly reported by head injured out-patients. These were used as a measure of frequency of memory failure throughout the programme (Figure 6.1) and were completed either jointly or individually on a daily basis.

III) **Mood**

The Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983). This is a brief self-assessment scale designed to detect anxiety and depression in non-psychiatric populations in medical settings. It includes 14 items, and a total possible score of 21, with a borderline range falling between 8-10.

IV) **Neuropsychological Assessment**

A full neuropsychological assessment was carried out at the 1st and 4th assessments. The 2nd and 3rd assessments consisted of the memory and concentration tests. Most of the instruments used in this study have demonstrated acceptable reliability and validity and are commonly used in traditional neuropsychological laboratory settings. Details

Figure 6.1: The Memory Checklist

NAME: _____

MEMORY CHECK LIST

DATE: _____

Please tick the items which occur each day. If you forget an item more than once, put a tick for EACH time it occurs.

	TICK EACH TIME IT OCCURS						
	Sun	Mon	Tues	Wed	Thu	Fri	Sat
1 Forgot to take pills							
2 Misplaced an item (eg spectacles)							
3 Lost concentration while reading							
4 Went into a room or shop - forgot what you went to get							
5 Forgot someone's name							
6 Forgot day/date							
7 Forgot to write down something important eg phone message							
8 Forgot what you read in a book/paper							
9 Forgot an appointment with a friend/doctor							
10 Forgot about a plan or arrange-ment you had made for the near future							
11 Forgot sequence of previous day's events							
12 Forgot sequence of today's events							
13 Forgot whether or not you did something you meant to do (eg post a letter)							
14 Lost concentration while listen-ing to conversation or television							

ADD any other things which you tend to forget

15 _____

16 _____

17 _____

18 _____

[redacted] patient version

regarding the tests can be found in Lezak (1983). Tests used in this study included:

1. **A short form of the Wechsler Adult Intelligence Scale** (Wechsler, 1955a), was used to assess current ability. Subtests chosen were: Similarities, Arithmetic, Digit Span, Block Design and Digit Symbol.

2. **The National Adult Reading Test** (Nelson, 1982) in order to obtain an estimate of pre-morbid ability.

3. **Logical Memory and Associate Learning from the Wechsler Memory Scale** (Wechsler, 1955b) were used to measure verbal memory and verbal learning, respectively.

4. **The Rey-Osterreith Complex Figure Test** (Osterreith, 1944; Taylor, 1969, 1979) was used to measure perceptual organisation and visual memory.

5. **The Paced Auditory Serial Addition Test (PASAT)** (Gronwall and Sampson, 1974) to measure ability to sustain concentration on a complex task.

6. **A Language Screen** to identify any expressive or receptive difficulties, included: The Token Test (Part V) (Boller and Vignolo, 1966), a short form of the Boston Naming Test (Kaplan et al, 1978), a Word Fluency Task (Borkowski, 1967), and a Repetition Task (Appendix).

When alternate forms of individual tests were available, these were administered sequentially in order to reduce practice effects.

Treatment Materials

Four memory aids/mnemonics were devised or adapted from the literature on cognitive remediation.

1. The first problem to be tackled was the patient's failure to remember the sequence and details of recent events. The **DAILY ACTIVITY SCHEDULE** (DAS) (see Figure 6.2) is a simplified diary or timetable which allows a whole week to be scanned at a time. Pictograms and simple wording enable it to be readily understood, even by patients with limited concentration or other cognitive impairments.

The DAS takes the form of a grid, with a square for each hour of the day for seven days. The patient is to make one or two word entries and draw 'pictograms' to provide 'at a glance' a record of daily activities (see sample DAS in Figure 6.3). Future commitments are entered in red ahead of time: these might include regular events such as remembering to take a pill or perhaps a social engagement. The purpose of the DAS is to cue recall of recent events, provide a summary record of what the patient has been doing and to provide an aid to structuring the days. Figure 6.4 displays the information handout given out with the DAS, suggesting uses for it.

2. **A DAILY DIARY** (Fig 6.5) is then introduced if patients have more detailed tasks to remember. The patient lists things to be done in the coming day and the times at which to do them. Patients are advised to tick off items as they complete them, for example, small chores such as shopping or making a phonecall.

3. The **PQRST** method (Figure 6.6) was originally a study method and has been described in student study manuals (e.g.

D A I L Y A C T I V I T Y S C H E D U L E

Figure 6.2 The Daily Activity Schedule

	8-9	9-10	10-11	11-12	12-1	1-2	2-3	3-4	4-5	5-6	6-7	7-8	8-9	9-10	10-11
MONDAY															
TUESDAY															
WEDNESDAY															
THURSDAY															
FRIDAY															
SATURDAY															
SUNDAY															

WEEK OF 23 Feb - 1st Mar.

Figure 6.3: Example of a Completed Daily Activity Schedule

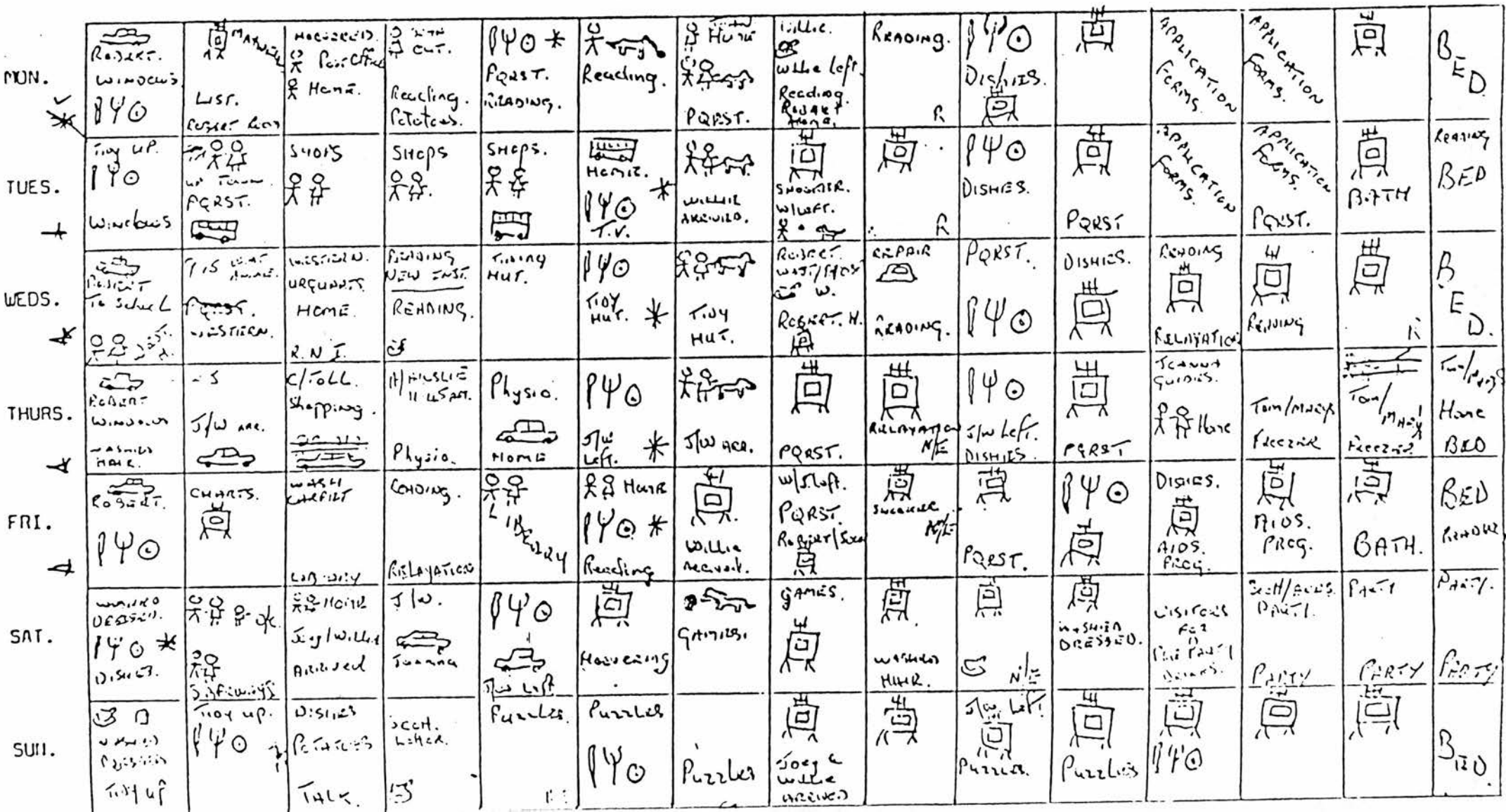


Figure 6.4: Instructions for Using the D.A.S.

DAILY ACTIVITY SCHEDULE

The Daily Activity Schedule (DAS) provides a way of keeping a record of your activities, which you can refer to for.....

(1) remembering events
(2) building a routine
(3) planning.

By providing a structure for past, present and future, it will prompt your memory to remember more detail.

1. RECORDING

Initially use the DAS as a basic record of your activities. Note briefly the activity you are doing at a particular time, making sure you note it *at the time of the activity*.

Using symbols or pictures can make it easy and quick to record and to read, e.g.

2. REMEMBERING

Once you have been using the DAS for a day or two, you can use it as an aid to remembering what you did, say, that morning, the day before, or even a few days before.

3. BUILDING A ROUTINE

Organize your time, using the DAS, so that those activities which you do everyday (e.g. taking pills, eating lunch, PQRST) are scheduled at the same time throughout the week.

Introduce any changes in your routine *one at a time, week by week*, to avoid confusion.

4. PLANNING

Make a note of planned events as soon as you know when they will be. For example, if you plan to meet a friend in a few days time, note their name and the place at the appropriate time.

If there are activities which you know you will be doing everyday at a certain time, write these in ahead of time, perhaps using red ink, so that you will know they are important.

OTHER USES.....

Gradually you may wish to become more spontaneous and flexible with your time. Each evening, or first thing in the morning, plan your day, ensuring that you include a variety of activites to make sure you are not spending too much time sitting around the house.

REMEMBER .....

- *You should look after your DAS yourself.*
- *It will help to prompt your memory.*
- *Your relative can help you plan your activities - but DAS is to help you be more independent in remembering them.*

Figure 6.5: Instructions for Using the Daily Diary

D A I L Y D I A R Y

A well structured diary is an important aid for remembering what you have set out to do during the day, and later making sure that you have done it.

You will need a pocket sized notebook, large enough to allow a page for each day.

Each morning (or the previous evening) make a list of the things you plan to do that day. Leave space on one side of the page wide enough to place a tick.

As you carry out each activity place a tick by it **AS SOON AS YOU HAVE DONE IT** - this is very important as it will be your way of knowing later on whether you have done that thing or not.

At the end of the day, check the list and see if anything has been left undone. If so, write it down on the page for the following day, so you do not neglect it.

For example,

DATE	TIME	ACTIVITY	TICK IF DONE
12/2	8.00	Take Pill	
	9.30	Go To Rehab.	
	10.30	'Phone Home	
	12.00	Post Letters	
	4.00	Pick Up John From Scouts	
	4.30	Buy Bread, Milk	
	6.00	Take Pill	
	7.30	PQRST	

REMEMBER - the diary will only be of practical use if you are able to remember to look at it regularly.

If you have an alarm, set it at regular intervals (say every two hours) to check you diary. Once this has become a habit, you may wish to use the alarm less frequently.

Figure 6.6: Instructions for Use the P.Q.R.S.T.

P Q R S T

PREVIEW Briefly skim to learn the general content.
LOOK FOR.....headings, main subjects.

QUESTION Ask and write down key questions

These might be.....who? what? when? where?
OR.....what are the 3 or 4 main points?

Don't answer questions yet!

READ Read actively, with the goal of answering the questions.
Read slowly and carefully - intend to remember.

STATE Go over the outline of what you've read - NOT word for word

Then lay it aside and recap.....
if you need to, read again to fill in the gaps.

Repeat a few times if necessary.

TEST Test yourself by answering the questions you posed earlier.

REMEMBER TO PRACTICE REGULARLY AT HOME

If possible, get your relative to test you ½ hour and 1 hour later.

Rate your recall each time on a scale of 0 - 10, on the sheets provided.

Also, try to remember 24 hours later.

(after F P Robinson, 1970)

Figure 6.7: Instructions for Us
Pinboard

PINBOARD

Hang the pinboard in a place where you will see it often, for example, in the kitchen. It can then be used as a reminder and source of new information, and can be helpful for organising your time and things you need to remember. Some uses are listed below, and you may think of others.

1. ORGANISING AND PLANNING

Divide the board into a few sections so that each person has their own area. In your section you may wish to keep a calendar, to remind you of the date, and planned activities.

2. REMEMBERING

Pin up a list of things which you find you regularly forget, e.g. taking pills, where you keep your spectacles etc.

3. REHEARSING

Names and faces: You may find it useful to pin up pictures of people whose names you often forget, with their names written below. You can test yourself regularly to see if you can remember their names without looking.

PQRST: Pin up 2 or 3 articles you are reading using PQRST, and briefly skim them when you pass the pinboard. This will help you retain the information between practice sessions. Change the articles every few days and replace them with new ones that interest you.

4. GETTING MESSAGES

The pinboard is a good place for others to leave messages for you and especially for letting you know if there is any change in a plan or routine.

5. LEAVING MESSAGES

If you want to let someone know something but aren't able to tell them immediately, write it down and pin it up on their section of the board. This is particularly important for 'phone messages, which can be easily forgotten.

6. MAPS

If you frequently forget the direction to places and how to get there (e.g. which bus number to take) pin a map up with the information necessary to get there. You can then take the map with you, and put it back on the board when you get back.

7. OTHER USES

The pinboard is also useful for keeping a list of telephone numbers, addresses, etc. or any information that you often need but may forget.

Robinson, 1970). It has been used increasingly in memory rehabilitation (Wilson, 1987; Koning-Haanstra et al, 1990). A simplified version of this was prepared. Its purpose is to aid patients in remembering what they have read - newspapers, books, their own diary, job instructions, etc. It provides a highly structured approach to reading and thus material. Such a method would be expected to facilitate encoding and thus enhance recall (Wilson, 1987). Study forms are provided to help patients follow each step until it has become habit. They also make a self-rating of their proficiency at recalling the material and make a note of any other reading (Appendix).

4. Finally, a **Pinboard** is positioned in a place where the patient will see it regularly. This can display incoming messages, reminders, articles being studied using PQRST etc. Clear guidelines are provided on how to use this (Figure 6.7). Other family members are also advised to use it to pass messages to each other, so that the patient feels less like the odd one out.

Additional material included:

5. **'Summary of the Effects of Severe Head Injury'**, a handout which provides a brief overview of the types of changes which commonly occur after severe head injury, the recovery process and sources of help available (Appendix).

6. **'Coping With Your Relatives Memory Problems':** a handout of basic guidelines to supplement treatment advice (Appendix).

7. Three social skills handouts, **CHAT, ACT and STOP, LOOK AND LISTEN**! (Appendix). These provide basic behavioural guidelines in regard to, respectively a) conversational

skills, b) assertiveness, and c) self-monitoring. These were designed to back up, when appropriate, advice given during treatment if and when relevant problems arose. This advice was provided on a flexible basis, as an adjunct to memory strategies.

Throughout treatment, the relative's help is considered fundamental. The relative identified to help with training participates in every session and time is also provided to allow patient and relative to discuss concerns separately. The role of the relative is twofold. He/she helps by recording day to day memory failures on the checklists. The relative also prompts the patient in use of the memory strategies, so that they become habitual. Prompts may at first be physical and verbal but gradually diminish in frequency over time.

PROCEDURE

Baseline

The initial assessment was carried out. If this provided evidence of memory deficit, in the absence of gross dysphasia or dyspraxia, the patient was considered to have the potential to benefit and was offered memory rehabilitation. Interview data from patient and relative and the presence of 1) sufficient patient insight to be willing to work and 2) sufficient relative support were further factors in this decision. To be considered able and willing to work closely in the memory treatment as co-therapist, the relative needed to be 1) living with the patient or in regular contact and 2) to be willing and able to complete memory checklists throughout the baseline and memory treatment phase. The relative was also expected to participate in treatment sessions on a regular basis.

Once these conditions were met, patient and relative were given a general outline of the nature of the programme. The use of memory checklists was explained and memory checklist forms supplied.

The 'Summary of the Effects of Severe Head Injury' was usually provided at this point, in order to provide basic information during what might otherwise have seemed a prolonged period of non-intervention.

A further baseline session was arranged to check that records were being kept and to identify and rectify any problems in this regard. This session was also aimed at maintaining morale and compliance in the absence of active treatment.

At the end of the baseline phase, memory checklists were collected and the total number of memory failures each week was recorded. The second assessment was then carried out.

Treatment Phase

In this phase, memory aids and mnemonics were introduced to the patient and relative. Only one method was introduced at a time and only after the previous method had become established. The relative was advised that his/her role was to ensure the patient used the method by prompting and/or reminding and that this might particularly be necessary in the beginning. The aim of having the methods become habitual was emphasized and reassurance given that memory impairment per se did not preclude this possibility. Handouts giving clear descriptions of each method were discussed in detail and participants were advised to refer to these regularly at home.

The treatment phase is described below, in a session by session layout. However, it was expected that patients would vary in the speed by which they adopted the techniques and the sessional format is used for descriptive purposes, rather than as a rigid timetable.

Treatment Session 1

The Daily Activity Schedule is introduced. The introductory Daily Activity Schedule (DAS) Sheet, an example of a completed DAS and blank DAS sheets are provided.

The patient's usual daily activities are discussed, for example, over the past week. Patients are encouraged to make brief notes and devise pictograms to represent frequently occurring activities, using the DAS example as

inspiration. A key to these is then recorded by the patient at the foot of the schedule. Together with patient and relative, a section of the DAS is filled in, for example covering the earlier part of the day of the visit to show clearly how it worked. The patient is also encouraged to try and remember the events of the previous few days or week, to highlight any difficulties with this kind of recall.

Following the initial treatment session, the patient is instructed to complete the DAS on a daily basis. If, as expected, the patient forgets to fill in part of the DAS, they are to use other sources of information, e.g. calendars, relative's prompting, to fill the gaps.

If patients balk at the amount of effort this would require, it is explained that making brief, personal notes throughout the day should actually only require a couple of minutes at a time, but that remembering to do this would be the more difficult task. The handout 'Coping With Your Relative's Memory Problems' is provided now for back up.

Treatment Session 2

The patient's DAS is looked at to confirm that it has been completed and practical suggestions are given to help the patient remember to do this. Information from the relative regarding the degree of help required to complete the DAS was also obtained. All efforts by both patient and relative to complete the DAS satisfactorily are praised and difficulties encountered treated sympathetically.

The past week is then reviewed with the patient, picking out particular events and asking further questions about them, using the DAS as a prompt.

Further aspects of the DAS are then discussed, such as planning future events, or incorporating a wider range of activities in his/her life, if repetition is apparent. The patient is then reminded of the future elements of the programme, but these are not to be introduced until the patient is very competent and comfortable in using the DAS.

Patients are advised to obtain a pocket sized notebook to bring to the next session when the Daily Diary will be introduced.

Treatment Session 3

The use of the DAS is reviewed and the procedure of the previous session is repeated in briefer form.

This session allows time for a separate discussion with the relative of any problems which may have been highlighted by the introduction of this strategy, such as increased insight, phobic behaviour or problems with mood or motivation. Problems raised will then be given attention in future sessions and obstacles to treatment tackled before proceeding with the introduction of further techniques.

The use of the Memory Checklist is reviewed as a means of pinpointing memory failures which have persisted despite using the DAS.

For those memory failures which have 'slipped through the net' of the DAS, the Daily Diary is then introduced. Its purpose and method are explained with discussion of the handouts.

Treatment Session 4

The Daily Diary and its accompanying handout are reviewed and its impact on the number of failures recorded on the checklist considered. If PQRST is to be introduced, a baseline record will have been completed by this point.

Treatment Session 5

PQRST is introduced. Reference to the baseline records is made to identify an appropriate level of difficulty as a starting point.

It is explained to both patient and relative that, whether or not one was a great reader before, the method's value is in improving retention of either reading material for pleasure or for conversation, or for learning about a new job or studying. In particular, it is stressed that to read in a structured way, with the intention of remembering points, is likely to result in more information being remembered than by an aimless scanning of articles, often with the presumption that nothing will be remembered anyway.

It is then introduced with a warning that it may involve quite a bit of effort initially, because of the learning involved, but that it will gradually become more automatic.

Patients are encouraged to identify material which would be of interest and in line with their ability, for example, beginning with short newspaper items and progressing on to magazines and then perhaps books of short stories. They are encouraged to set up a time to practise PQRST when relatives will be available, so that they can test themselves and also be tested on their answers. The self-rating scales used as a baseline measure also serve to record PQRST ratings of success and for noting the amount of reading done.

Treatment Session 6

The Pinboard is introduced, provided one has been obtained. The handout is discussed and its main points emphasised because of the apparent simplicity and obviousness. The Pinboard is intended to underpin the use of the previous methods. Patients and relatives are advised to position the pinboard in a place that is convenient and frequently passed, and it is suggested that they quickly scan the information on it each time they pass it, in case of any change (e.g. recent phone messages) or to quickly practice PQRST.

Treatment Session 7

Further sessions consist of a review and consolidation of all the methods along the lines which have been building up, but were spaced further out to 2 or 3 week intervals. Memory Checklists are reviewed to note any outstanding memory failures, which are tackled through the use of existing techniques or practising alternatives.

If Social Skills Training has been decided upon as an adjunct to memory training, this is introduced during these latter sessions. Handouts for these are provided and discussed and video-tape sessions or roleplay arranged if patients are agreeable. The principles behind the handouts are discussed with both participants and homework exercise given to encourage the patient to rehearse appropriate behaviours in real-life settings.

End of Treatment Assessment

Follow-up arrangements are made with further record forms to be mailed out in order to be completed before the final

follow-up assessment.

Follow-up

The final assessment is carried out. In addition, a supply of the relevant forms is provided. If it has not been done so already, any arrangements to refer the patient and/or relative to other professionals are made now.

CHAPTER VII

Results

RESULTS

Analysis of Data

The main findings of this study are presented as individual case studies. Statistics are descriptive rather than inferential, geared to understanding of individual performance. The use of this procedure for single case design is well supported (Hersen and Barlow, 1976), and is considered particularly valuable in head injury research (Adamovitch, 1985, Wilson, 1987, Gianutsos and Gianutsos, 1979). The multiple baseline across subjects part of the study is used as the basis for discussion in the next chapter.

Table 7.1 provides a summary of the Demographic and details of the subjects in the study. Individual demographic and neurological details can be seen in Table 7.2. Overall, the subjects were largely young adults, well past the period of most rapid recovery. Two had sustained very severe injuries and the remainder were extremely severe. Subjects were evenly distributed between the sexes. All but one had been employed prior to injury and none were employed prior to treatment. Most were children being cared for in some capacity by their parents, and only two were married.

Table 7.1: Summary of Demographic Characteristics of Cases 1 - 10

	Range	Mean	S.D.
Age	18-48 years	27.6	8.95
Time post-injury	7-48 months	18.7	12.55
P.T.A.*	14-180 days	64.9	48.71
R.A.**	1-730 days	177.70	229.15
Premorbid I.Q.***	95-118	108.60	7.80
Current I.Q.	87-110	94.6	7.13

* Post-Traumatic Amnesia
** Retrograde Amnesia
*** Pre-morbid Intelligence estimated from the National Adult Reading Test (Nelson, 1982)

Table 7.2: Demographic and Neurological Details - Cases 1-10

Case	Age	T.P.I.‡	P.T.A.‡‡	R.A.‡‡‡	Sex	Previous Employment	Present Employment	Relative Helping
1	23	1 year	2 ½ months	3 months	Female	Supermarket Clerkess	None	Husband
2	23	1 ½ years	3 months	3 hours	Male	Business Trainee	None	Mother
3	28	3 years	1 month	1 year	Male	Antique Dealer	None	Father
4	48	4 years	2 months	7 days	Male	Boilermaker	None	Wife
5	25	1 year	3 ½ months	6 months	Female	Civil Servant	None	Mother
6	18	1 ½ years	1 months	1 month	Female	Apprentice Joiner	None	Mother
7	21	1 ½ years	6 months	2 years	Male	University Student	None	Mother
8	21	9 months	1 months	1 year	Female	Sewing Machinist	None	Mother
9	40	9 months	14 days	7 days	Female	Housewife	Same	Son
10	29	7 months	21 days	2 days	Male	Production Manager	None	Wife

‡ Time post-injury
‡‡ Post-traumatic Amnesia
‡‡‡ Retrograde Amnesia

CASE STUDIES

Case # 1 (S.D.)

Demographic and Family Setting

S. was a 23 year-old woman who sustained an extremely severe head injury in a road traffic accident. By her own account, her period of post-traumatic amnesia was three months (Table 7.2), but her husband considered it to be closer to six months. At the time of her accident, S. was married and worked as a supermarket clerkess. Her husband worked as a garage mechanic.

Neuropsychological Profile

The results of S.'s neuropsychological assessments are provided in Table 7.3. These suggested very significant global memory problems prior to treatment. She demonstrated marked visuospatial problems, and was unable to read normal sized print. She also showed expressive language difficulties, and tended to get her words muddled up in discourse. Her average intellectual ability fell in line with her estimated pre-morbid level of ability.

Day to Day Memory

Tables 7.4 and 7.5 shows the results of the Patient and Relative versions of the Everyday Memory Questionnaire and Cognitive Failures Qustionnaire. Individual items occurring frequently included forgetting messages, losing track of a T.V. program, repeating herself, and forgetting previous or planned events. S. insisted she was 'just the same as before' in this regard. On both questionnaires her husband's report largely agreed in terms of the types of error, but noted a higher frequency of forgetting. He also indicated that S. led a rather restricted lifestyle which

Case # 1 (S.D.)

Table 7.3: Neuropsychological Data for Case # 1

	Assessment # †			
	1	2	3	4
Logical Memory*				
Immediate	2/23	2/23	3/23	8/23
Delayed	1/23	2/23	2/23	3/23
Paired Associates*				
Easy	8	7	9	7
Hard	2	3	2	5
Total	10	10	11	12
Rey-Osterreith*				
Copy	12/36	21/36	24/36	30/36
Immediate Recall	7	10	9	16
P.A.S.A.T.				
4 seconds	unable to do		unable to do	
2 seconds	unable to do		unable to do	
W.A.I.S.- R.**				
Similarities	8		9	
Arithmetic	5		5	
Digit Span	7		10	
Block Design	7		6	
Digit Symbol	unable to do		3	
F.S.I.Q.***	87		84	
N.A.R.T.****	100			
Boston Naming Test	27/60		49/60	
Word Fluency*				
Category	10		12	
Easy letter	14		16	
Hard letter	4		7	
Repetition	100/100		90/100	
Token Test	21/21		21/21	

* Alternative forms administered.
** Age scale scores.
*** Full Scale I.Q.
**** National Adult Reading Test

† NOTE: An explanation of the timing of the assessments in general is given on pages 54 & 55. The precise timing for each case is provided as part of the case description.

Case # 1 (S.D.)

Day to Day Memory Questionnaires

Table 7.4: Everyday Memory Questionnaire*

Assessment #	1	2	3	4
Patient	48(38)*	40(31)	26(20)	21(16)
Relative	99(77)	91(71)	32(25)	34(27)
Agreement **	12/15 (80%)	10/16 (63%)	5/9 (56%)	9/15 (60%)

Table 7.5: Cognitive Failures Questionnaire*

Assessment #	1	2	3	4
Patient	26(26)	9(9)	10(10)	22(22)
Relative	18(56)	16(50)	16(50)	16(50)

Psychosocial Data

Table 7.6: Hospital Anxiety and Depression Scale

Assessment #		1	2	3	4
Anxiety	- Patient	0	2	3	4
	- Relative	7	6	7	4
Depression	- Patient	1	5	3	6
	- Relative	4	4	6	3

Table 7.7: Subjective Burden

Assessment #	1	2	3	4
Patient	0	5	3	0
Relative	6	3	7	7

*Figures in parentheses are percentages of total possible score, as questionnaires differ in total number of items.
**% agreement by patient and relative on items endorsed.

reduced the opportunity for forgetting. This involved unsolicited domestic and transport assistance from her in-laws, but S. also used her stick as an excuse for not going out.

Psychosocial Profile

At her initial pre-treatment assessment, S. acknowledged only minimal symptoms of anxiety or depression (Table 7.4) and denied experiencing any degree of subjective burden (Table 7.7). At the end of the six week baseline period, both of these measures showed an increase. Her husband, however, experienced moderate stress levels at both pre-treatment assessments.

Problems reported on interview

Table 7.8 shows the problems endorsed on the Interview Questionnaire by S. and her husband both before and after treatment. Their reports show a wide discrepancy regarding the number of problems present prior to treatment. Whereas S. described herself as essentially unchanged, apart from difficulties in language and vision, her husband reported several psychological and behavioural changes since her accident. S.'s comments suggested a tendency to play down her problems. She considered her memory to be 'rather' poor since her injury, but insisted that this had always been the case, and described herself as having been a forgetful, absent-minded person. She felt that her concentration was fine. Her husband, A. reported that although S. experienced everyday memory problems, these were largely avoided through her inactivity and the presence of others to remind her of things. Physically, S. suffered from poor balance for which she used a stick and was on medication for fits although she had none to date. S. was attending a Day Centre, and received Speech therapy at this time.

Case # 1 (S.D.)

Table 7.8: Problems Reported on Interview

	Pre-treatment		Post-treatment	
	Patient	Relative	Patient	Relative
Vision		+	+	+
Balance		+	+	+
Headaches	+		+	
Tiredness		+		+
Slowness		+		+
Tension/Anxiety		+		+
Impatience		+		+
Irritability		+		
Temper		+		+
Violence				+
Speech	+	+	+	+
Wordfinding	+	+	+	+
Understanding	+	+		
Concentration			+	
Memory		+	+	+
Depression				+
Moodiness		+		+
Personality Change		+		+
'Not bothered'		+	+	+
Disabled/dependant		+		+
Supervision	+	+		+
Job Prospects		+		+
Leisure/Social	+	+		+
Sex Life				+
Total	6	20	8	20
Agreement*:	**Pre-** 25%		**Post-** 27%	

*Percentage of agreement between patient and relative on problems endorsed on interview questionnaire.

Treatment

Memory Checklists were completed by S. herself, in view of her husband's absence during the day. Over the six week baseline period, S.'s weekly frequency of memory failures ranged between eleven and six, as recorded by S. on the Memory Checklists (Table 7.9).

Treatment was aimed at introducing memory strategies, beginning with the DAS, to help S. with her memory, but also to encourage her to become self-reliant. Her memory problems appeared to be masked by her reliance on others to provide information for her, without first trying to find the answer herself. It appeared that S. needed to develop more insight into her memory problems in order for her to reliably use memory strategies. The slight increase in her psychosocial stress scores over the baseline period suggested that psychological factors led her to play down her problems, and that the act of keeping a baseline record had increased both the degree of her awareness, and the degree of stress. Her husband appeared to be a willing co-therapist, but also eager to protect S. from any distress. Encouraging him to 'let go' of S. to allow her to make and correct her own mistakes was therefore a further goal.

Treatment strategies for S. included introduction of the three main compensatory strategies, i.e. Daily Activity Schedule, Daily Diary and Pinboard, and a plan to introduce PQRST if reading ability allowed. The possibility of limited social skills training to develop S.'s insight and reduce her tendency to mask problems was also considered, but held until the primary memory strategies were well-established. The plan was discussed with the couple and followed closely to the treatment procedure described earlier.

Treatment - Case 1 (S.D.)

Table 7.9: Total number of reported memory failures per week during baseline and training phases as recorded on Memory Checklists.

Week #	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
Baseline (P)*	11	11	7	6	7	6												
Treatment (P)	3	0	3	0	0	2	0	0	2	2	1	3	2	0	0	0	0	0
Follow-up (P)	0	0																

* Recorded by patient

Table 7.10. Patient's Self-Rating of Successful Recall of Material Studied using the 'PQRST' Method (10 = good, 0 = poor).

	1	2	3	4	5	
Baseline	0	0	0	0		
Treatment	7	9	7	6	7	(recall after ½ hour)
	10	9	8	6	6	(recall after 1 hour)
	3	7	6	5	5	(recall after 24 hours)
Follow-up	6	7				
	5	6				
	5	5				

At her initial treatment session, S. reported that she was no longer forgetting anything, as her MCL was enough of a reminder, but A. said she still forgot 'a few things'. Treatment was thus described to her as 'fine tuning' which she found easy to accept. Introduction of the DAS highlighted a number of memory failures on the spot, which she willingly acknowledged. S. was adept at devising pictograms, which she found easier to execute and interpret than handwriting (Fig 7.1). The DAS also showed clearly how S. used her time, and she was encouraged to plan a variety of activities outside the home in order to build up her confidence (Fig 7.2). Training in the use of the Daily Diary and Pinboard continued smoothly, with S. consistently attempting and then using each technique. S.'s regular attendance at the day centre enabled her Occupational Therapist to back up S.'s use of the strategies. Table 7.9 shows that over the 18 weeks of treatment, S.'s moderate number of memory failures gradually diminished to none at all by Week 14. In view of her improved reading ability, a baseline for PQRST was kept, and showed no recall for any of the articles read. Despite this, her use of the PQRST technique appeared to be successful (Table 7.10). Her self-ratings indicated an immediate sense of efficacy at recall after ½ hour and 1 hour, with diminishing, but evident success at recalling articles after 24 hours. Her husband confirmed that she was benefiting from the techniques, and that, she clearly enjoyed the discipline and benefit they provided.

S. responded well to encouragement to become more independent and found she was able to go out without supervision and to walk without support. By her 4th session, S. was walking outdoors more, and her social life had improved. Her reading and comprehension had also continued to improve. Despite these improvements, however,

Figure 7.1: Example of S.D.'s Pictograms

WEEK OF 1st January

Figure 7.2

Example of S.D.'s D.A.S.

DAILY ACTIVITY SCHEDULE

	8-9	9-10	10-11	11.12	12-1	1-2	2-3	3-4	4-5	5-6	6-7	7-8	8-9	9-10	10-11
MON.															
TUES.		chat	meeting with Joyce		wash		chat		Shaving		Photos		phone		
WEDS.				assessment allowance meeting		chat			chat	Dyed Hair					
THURS.		chat		chat		chat		shopping	shoping Home	Tidy up house			House Work		
FRI.							tidied up		watering plants	Got ten ready.		washed Dishes			
SAT.			Made Bed			Bathroom shoping				Home		planted Bonsai		Get bedroom ready.	
SUN.			Tidied up	Tidied up move.		chat	walk	washing dishes.	shoping		Tidied up				

PLEASE RECORD BRIEFLY THE ACTIVITY CARRIED OUT AT A PARTICULAR TIME (E.G LUNCH, HAVING VISITORS, USING COMPUTER, RESTING ETC).

TRY TO WRITE IT AS PROMPTLY AS POSSIBLE.

S. complained of feeling low, and having to tell herself she 'could be worse off'. She also complained privately that her husband was 'less fun' and less communicative than he had been, and she felt he was away at work too much. For the first time, S. admitted that she bluffed a lot to cover up her problems. She began to complain of her in-laws' over protectiveness, and S. had argued with them about the 'help' they gave her. Treatment at this point became geared to encouraging S.'s increased insight and independence but teaching her ways of managing the conflicts which were arising as a result. Video-tape sessions were introduced, based on the social skills described in the ACT and CHAT handouts, in order to improve S.'s assertiveness and problem-solving skills.

Over the remainder of the treatment period, S. began to notice improvements in her family situation. She was able to discuss openly her increased awareness, and described herself as 'more serious, yet more cheerful' than she had been previously. By the final sessions, S. was using mnemonic strategies regularly, without prompting, although she abandoned the DAS for a journal which she kept at night. both S. and her husband felt they were now communicating well, and that S. was remembering better than she had been prior to treatment. near the end of treatment they went on holiday and met people whom S. had known before her injury. She felt at ease in this situation which seemed to test her progress in all the areas tackled during treatment.

Post-Treatment

As shown in Table 7.9, two months following the end of treatment, S. was maintaining the progress she had made in using the memory strategies. Her PQRST self-ratings also indicated that her improvement had been maintained (Table

7.10). This progress was reflected in her scores on the Everyday Memory Questionnaire, which decreased by more than 50% (Table 7.4). Her husband's scores also agreed in this respect, but there was now less agreement regarding the types of errors made. On the Cognitive Failures Questionnaire (Table 7.5), her score at the end of treatment was in line with that at the end of the baseline period. However, this rose again to nearly its original level by follow-up. Her husband's scores on this measure remained largely unchanged at all four assessments. On formal testing, she showed very slight improvement in overall memory performance, in her psychomotor coordination, and expressive ability (Table 7.3).

Psychosocial measures did not reflect the improvement in R.'s day to day memory (Table 7.4 & 7.5). Tables 7.6 and 7.7 show a moderate increase in her scores on both the Hospital Anxiety and Depression Scale and Subjective Burden, while her husband's scores remained largely unchanged. S.'s report of problems on interview at follow-up was largely unchanged, although she now acknowledged memory to be a problem, and considered herself more independent. Her husband, however, reported an improvement in S.'s language abilities, but a deterioration in her behaviour, mood and their sex life (Table 7.8). He described S. as pushing him physically if she was thwarted in her wishes, and she had begun to spend money recklessly. She had also been caught shoplifting. S. herself denied the significance of these problems, and their relation to her head injury. It appeared that S.'s increased insight had enabled her to cope with everyday memory problems, but had also raised deeper problems of adjustment which needed attention. Because of these problems, which had evolved during the post-treatment period, S. was referred to another Clinical Psychologist in her area.

Case # 2 (A.M.)

Demographic and Family Setting

A.M. was a 23 year-old business trainee who sustained an extremely severe head injury in a motorcycle accident, for which he was to blame. His post traumatic amnesia was approximately three months and his retrograde amnesia was only one day (Table 7.2). At the time of his accident, A. was training in his father's business and lived at home with his parents and younger brother.

Neuropsychological Profile

As can be seen in Table 7.11 formal assessment suggested that A. had difficulty in attention, concentration and learning new information. He showed sound reasoning abilities, but was somewhat slow on non-verbal tasks. He had no gross language difficulties.

Day to Day Memory

A. reported moderate everyday memory problems (Table 7.12). Perhaps surprisingly, his mother reported a lower frequency of everyday memory problems than A. himself, and there was only modest agreement regarding the nature of his memory problems. On the Cognitive Failures Questionnaire (Table 7.13), A. reported few problems, occurring infrequently. On this, his mother reported a higher degree of absent-mindedness.

Psychosocial Profile

A. reported few symptoms of anxiety and depression at either pre-treatment assessment (Table 7.14). He initially

Case # 1 (A.M.)

Table 7.11: Neuropsychological Data for Case # 2

	Assessment #†			
	1	2	3	4
Logical Memory*				
Immediate	12/23	9/23	9.5/23	10/23
Delayed	11/23	5/23	7.5/23	6/23
Paired Associates*				
Easy	9	6.5	9	8.5
Hard	3	6	9	7
Total	12	12.5	18	15.5
Rey-Osterreith*				
Copy	36	36	36	36
Immediate Recall	16	15	16	21
P.A.S.A.T.				
4 seconds	43/60	43/60	46/60	47/60
2 seconds	24/60	29/60	21/60	24/60
W.A.I.S.- R.**				
Similarities	11		10	
Arithmetic	11		11	
Digit Span	11		9	
Block Design	5		5	
Digit Symbol	6		6	
F.S.I.Q.***	94		91	
N.A.R.T.****	100			
Boston Naming Test	48/60		54/60	
Word Fluency*				
Category	16		13	
Easy letter	12		13	
Hard letter	7		7	
Repetition	100/100		100/100	
Token Test	21/21		21/21	

** Age Scale Scores
* Alternate Forms
*** Full Scale I.Q.
**** National Adult Reading Test

† NOTE: An explanation of the timing of the assessments in general is given on pages 54 & 55. The precise timing for each case is provided as part of the case description.

Case # 2 (A.M.)

Day to Day Memory Questionnaires

Table 7.12:Everyday Memory Questionnaire*

Assessment #	1	2	3	4
Patient	58(45)*	46(36)	37(29)	38(30)
Relative	25(20)	24(19)	38(30)	25(20)
Agreement **	5/15 (33%)	4/14 (29%)	13/16 (81%)	8/14 (57%)

Table 7.13:Cognitive Failures Questionnaire*

Assessment #	1	2	3	4
Patient	19(19)*	25(25)	41(41)	31(31)
Relative	15(47)	11(34)	12(38)	15(47)

Psychosocial Data

Table 7.14:Hospital Anxiety and Depression Scale

Assessment #		1	2	3	4
Anxiety	- Patient	4	4	2	2
	- Relative	5	6	11	11
Depression	- Patient	2	1	5	2
	- Relative	4	4	5	5

Table 7.15:Subjective Burden

Assessment #	1	2	3	4
Patient	6	1	1	0
Relative	5	1	1	2

*Figures in parentheses are percentages of total possible score, as questionnaires differ in total number of items.
**% agreement by patient and relative on items endorsed.

reported a moderate degree of subjective burden resulting from his head injury, but over the baseline period this lessened to virtually nil (Table 7.15). His mother's scores closely mirrored A.'s. This congruence was also evident in their presentation. A. came across as an extremely unworried person, but with a tendency to agree a bit too readily. His mother, despite the possible impact of the accident on A.'s future, also appeared cheerful and untroubled, yet not indifferent.

Problems Reported on Interview

A. reported that his memory was much worse since his accident, but he was vague when asked to give examples of specific incidents of forgetting. He appeared almost completely untroubled by this himself, but his parents were concerned about his ability to resume his training in the family business which, it was hoped, A. would one day manage. A. also complained of problems with his balance and hearing, but most notably he suffered from grand mal seizures, approximately once a month. Table 7.16 shows the problems reported by A. and his parents both before and after treatment. A.'s parents emphasized that A. was never on his own because of his epilepsy and this greatly reduced the opportunity for memory problems to occur. He described himself as working part-time in a joiner shop, although in fact this was a setting within the Day Centre that he attended.

Treatment

Jointly recorded memory failures over the baseline period were very stable (Table 7.16), falling between 15 and 17 per week. The types of failure recorded appeared trivial (e.g. what he had eaten for his most recent meal), yet A. stressed

Case # 2 (A.M.)

Table 7.16: Problems Reported on Interview

	Pre-treatment		Post-treatment	
	Patient	Relative	Patient	Relative
Vision	+	+	+	+
Hearing	+	+	+	+
Balance	+	+	+	
Epilepsy	+	+	+	+
Tiredness				+
Sleep Disturbance	+			
Slowness	+	+	+	+
Tension/Anxiety		+		
Temper	+			
Speech		+		+
Wordfinding	+	+	+	+
Understanding	+			
Concentration	+	+	+	+
Memory	+	+	+	+
Childishness	+	+		+
Personality Change	+	+	+	+
'Not bothered'			+	
Disabled/Dependent		+	+	+
Supervision		+		+
Job Prospects	+	+	+	+
Leisure/Social	+	+	+	+
Total	15	16	12	15

Agreement*: **Pre-** 63% **Post-** 65%

*Percentage of agreement between patient and relative on problems endorsed on interview questionnaire.

their importance to him. A.'s very low frequency of memory failures as recorded on his MCL's, and his apparent lack of concern about these initially seemed not to justify a highly structured and sustained treatment effort. However, his subjective experience of poor memory and his intention to return to work, together with the overprotective attitude of his mother and his lack of independence seemed worthwhile treatment targets. To be effective, treatment therefore involved introducing the strategies in such a way that A. would accept them as analogues to work timetables and diaries rather than as a prosthetic system for a memory impairment which he found hard to acknowledge. A second aim was to increase A.'s level of independence, as it was clear that he was being sheltered from age appropriate activities as well as from testing his memory in more difficult situations. It was also considered that A.'s tendency to yea-say was possibly a device to avoid conflict, and although this seemed likely to have been a pre-morbid characteristic (consistent with his family's functioning) it seemed that it could hinder him from admitting memory problems to others when this might be necessary, e.g. if put under pressure. Therefore, some social skills training toward the end of the treatment was a tertiary aim. All four memory strategies were introduced, according to the treatment outline, in addition CHAT and ACT were integrated later on.

Treatment consisted of twenty sessions. Table 7.17 shows that from the onset of treatment, A. showed an immediate reduction in the number of memory failures recorded weekly. The introduction of the DAS appeared to 'catch' a number of memory failures and with the gradual introduction of the Daily Diary and Pinboard, his reported everyday memory problems were few. From week 7, he recorded virtually no memory failures, and his mother's record showed close

CASE # 2 (A.M.)

Table 7.17 :Total number of reported memory failures per week during baseline and training phases as recorded on Memory Checklists

	Week #	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22
Baseline (Pt)		15	15	16	16	17	16																
Treatment (Pt)		5	1	3	3	3	2	0	0	2	0	0	0	1	0	0	0	0	0	0	0	0	0
(Rel)		5	2	3	3	3	2	0	1	2	1	2	1	2	0	1	1	2	1	0	1		
Follow Up (Pt)		2	2																				
(Rel)		1	1																				

Table 7.18 :Patient's Self-Rating of Successful Recall of Material Studied using the 'PQRST' Method (10 = good, 0 = poor)

		1	2	3	4	5	6	7	8	9	10	11	12	13	14
‡ Recorded by Patient	(½ hour)	4	5	5											
	(1 hour)	3	3	3											
	(24 hours)	Not Recorded													
Treatment	(½ hour)	6.7	7.7	7.4	7.3	7.6	7.6	8	7.6	8.5	6.8	8.3	8.3	8.0	9.0	7.8
	(1 hour)	7	7	7.9	8.4	8.2	7.9	8.4	8	8.4	9.0	8.9	9.2	9.0	7.8	7.3
	(24 hours)	7.3	7.2	8	7.6	8.6	8.4	8.4	8.3	9.2	9.3	9.1	8.7	9.5	8.7	7.5
Follow Up	(½ hour)	7	7.25													
	(1 hour)	8.2	8.25													
	(24 hours)	8.25	8.25													

agreement. His use of PQRST also appeared to be successful. Having recalled nothing of the articles read over the baseline period, he felt immediate benefit from the technique and this is reflected in his self-ratings (Table 7.18). His mother initially found that he needed pushing in order to practice this, but gradually sat down to it on his own initiative. Examples of A.'s DAS AND PQRST exercises can be seen in Fig 7.3 and Fig 7.4.

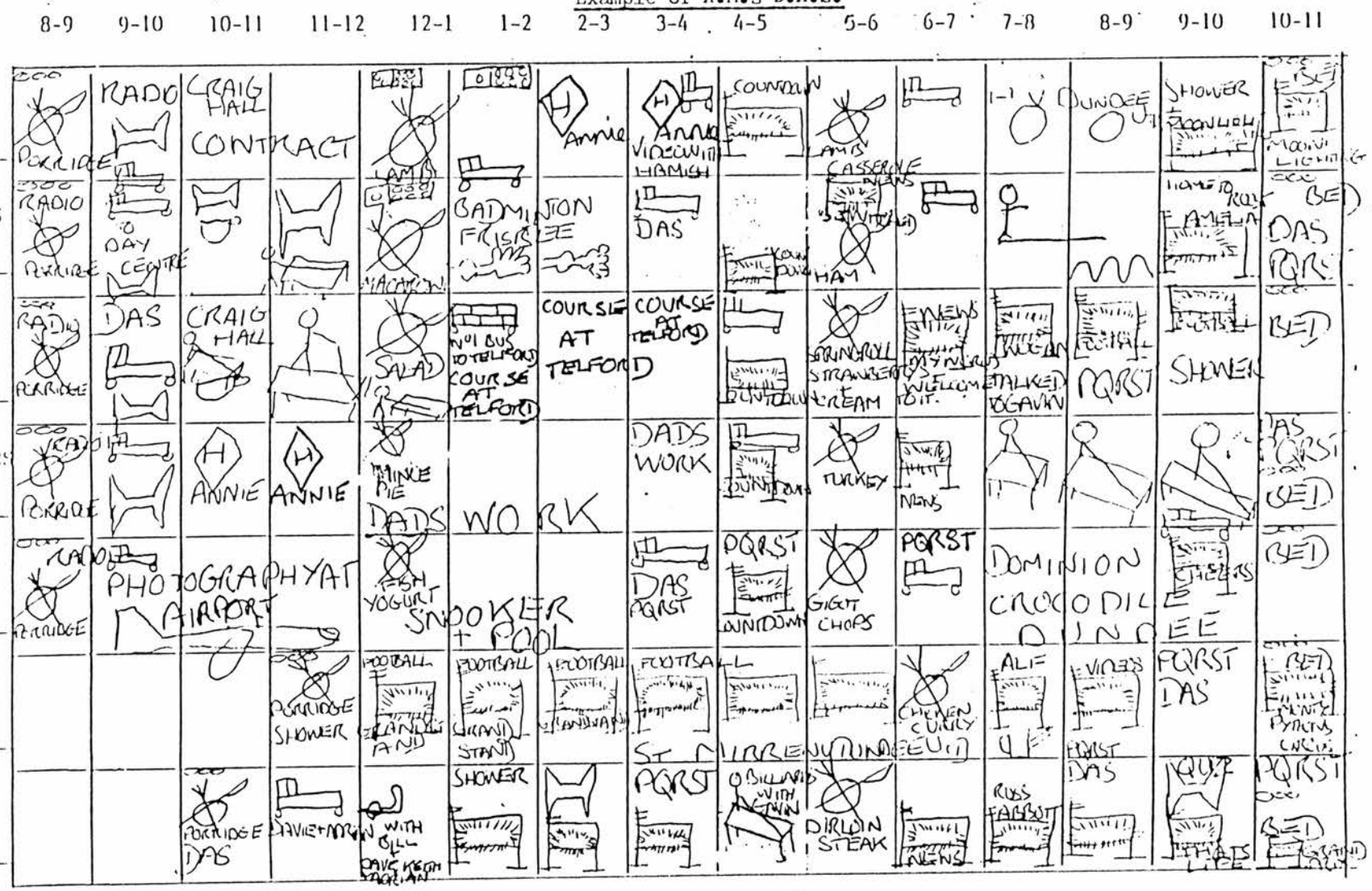
A.'s DAS was used as a basis for discussion about his insular, family bound lifestyle, and he was encouraged to identify activities enjoyed prior to his accident to which he could realistically return. He began to take on more demanding activities, including attending a college course to repeat a Higher Certificate course which he had passed prior to his injury, but much of which he had forgotten. His father was able to provide work for A. at his office one day each week and this progressed from very simple arithmetic to compiling and computing VAT forms. He continued to attend the Day Centre, where he began to train in the use of computers, which he found very difficult. A. was encouraged to apply the PQRST system in each of these settings, where his efforts were backed up by staff.

Exposed to new situations, A. found that he lacked social confidence and became anxious and avoidant, for example, when in the college cafeteria. In addition, he described certain activities at the day centre to which he felt relegated and did not enjoy, yet felt unable to ask for these to be changed for fear of upsetting others. His difficulty in assertion was also characteristic of his parents, who also sought advice during treatment regarding situations, particularly those in which they felt A. was tied to a disabled identity, from which they would like to extricate themselves. Other anxieties also surfaced as A.

DAILY ACTIVITY SCHEDULE

WEEK OF 11TH MAY - 17TH

Figure 7.3
Example of A.M.s D.A.S.



KEY:

Figure 7.4

Example of A.M.'s P.Q.R.S.T. Study Form

PQRST JUNE 22ND

PREVIEW ALAN HEALEY HAS THE SAME HAND COMPLAINT THAT MRS THAT
HAD BUT MRS THATCHER GOT IMMEDIATE PRIVATE ATTENTION WHEREAS ALA
WAITED 8 YEARS AND HAS HAD TWO FINGERS AMPUTATED

QUESTION 1) WHO
2) WHAT
3) WHERE
4) WHEN

REVIEW THATCHER OR MAN'S YEARS OF PAIN

STATE ALAN HEALEY 58. CONTRACTED DUPUYTREN'S CONTRACTURE WHICH MRS TH
PAYED FOR PRIVATE ATTENTION

TEST 1) ALAN HEALEY
2) CONTRACTED DUPUYTREN'S CONTRACTURE
3) OLDHAM
4) 8 YEARS AGO

became more independent. His mother expressed concerns about his welfare when out on his own, in case he should have a fit, and they had begun to argue occasionally about what he should be allowed to do on his own. When these issues were discussed openly, it emerged that Mrs M. blamed herself for A.'s accident because she had not originally put her foot down and not allowed him to have a motorbike. On hearing this, apparently for the first time, A. smiled and said, 'But it was my fault, mom. I was drinking before the accident'. While Mrs M . found it very difficult to hear that her 'ideal' eldest son may have contributed to his present condition in this way, this became a turning point for her in 'letting go' of A. and in getting on with her own life instead of protecting A. For A., it was an unusual event, in that he brought himself to say something potentially upsetting to another. Following on from this, role play exercises using CHAT and ACT were introduced and A. given feedback regarding his efforts to initiate and sustain conversations. Homework exercises included saying 'no' to people regarding activities he found uninteresting or difficult but also making sure that he was not dismissing as 'boring' things which were in fact taxing but important.

Near the end of treatment, A. went on a one week sailing course which had no associations with his head injury, and was in no way monitored by his parents. Indeed, A. left all of his mnemonic strategies at home deliberately. He returned appearing confident in having demonstrated his ability to cope physically and psychologically independent from his parents (and psychologist). At his final session, he reported that he was no longer forgetting anything and had not done so for several weeks. he expected to continue using the techniques but would no longer use PQRST formally, as it had largely become automatic. His mother said he spoke up more than he had prior to his injury and said that

they now argued occasionally but she felt this was appropriate. A.'s next step was to continue college and then hopefully return to work, albeit in a lesser capacity than he had been prior to his injury.

Post-Treatment

Table 7.17 shows that A. continued to benefit from the memory strategies at a 2 month follow-up. His success with PQRST also appeared to be maintained (Table 7.18), despite his now infrequent rehearsal of the technique. His mother confirmed that this was the case. His score on the Everyday Memory Questionnaire reflected this improvement, but his mother's already modest score remained unchanged at follow-up (Table 7.12) and there was closer agreement in the type of memory failures noted. His score on the Cognitive Failures Questionnaire rose over the treatment period, and he was more inclined to admit to absent-mindedness, while his mother's score was in line with that initially (Table 7.13). Formal neuropsychological testing showed a very slight improvement in memory scores, but no overall improvement.

This improvement in day to day memory was paralleled by a reduction in the Subjective Burden experienced by both A. and his mother, diminishing from moderate to none, or virtually none, respectively (Table 7.15). While A.'s mood remained stable throughout the programme, his mother's anxiety rose to a clinical level by the end of treatment and remained so at follow-up. This appeared to stem from her concerns regarding A.'s independence, and she was aware of a fear that he would experience further injury. Problems reported on interview were largely unchanged, and agreement continued to be reasonably close, (Table 7.16).

Case # 3 (C.H.)

Demographic and Family Setting

C.H. was a 28 year-old man who sustained an extremely severe head injury in a road traffic accident. His period of post-traumatic amnesia was 30 days (Table 7.2). His period of retrograde amnesia was extensive, at least one year, and he had virtually no memory of his infant son, and only very patchy memory for his marriage. At the time of his injury he was working in the family antique business. His marriage broke down soon after his injury because of personality changes resulting from the accident. At the time that C. entered the rehabilitation programme he was living with his parents and younger brother, and working in a very sheltered capacity in the family business.

Neuropsychological Profile

The results of C.'s assessments can be seen in Table 7.19. He demonstrated global memory and concentration deficits, and his performance was marked by distractability, confabulation and perseveration. He repeatedly required steering back to the task at hand and frequently interrupted to make inappropriate personal and sexual remarks and jokes. These features were consistent with damage to the frontal lobes, and this was consistent with the nature of his injury. No gross language problems were evident, but he had a tendency to slur and to get off track in discourse. Although his vision was worse since his injury, he was able to read normally.

Day to Day Memory

C.'s scores on the measures of everyday memory problems

Case # 3 (C.H.)

Table 7.19: Neuropsychological Data for Case # 3

	Assessment # †			
	1	2	3	4
Logical Memory*				
Immediate	13/23	6/23	7/23	9/23
Delayed	7/23	4/23	7/23	5/23
Paired Associates*				
Easy	7	8	7	9
Hard	3	3	4	2
Total	10	11	11	11
Rey-Osterreith*				
Copy	36/36	35/36	36/36	35/36
Immediate Recall	9/36	7/36	12/36	9/36
P.A.S.A.T.				
4 seconds	50/60	54/60	51/60	53/60
2 seconds	28/60	29/60	34/60	18/60
W.A.I.S.- R.**				
Similarities	11		10	
Arithmetic	11		13	
Digit Span	10		10	
Block Design	8		8	
Digit Symbol	5		7	
F.S.I.Q.***	95		98	
N.A.R.T.****	103			
Boston Naming Test	35/60		39/60	
Word Fluency*				
Category	18		17	
Easy letter	18		12	
Hard letter	5		4	
Repetition	100/100		100/100	
Token Test	21/21		21/21	

** Age Scale Scores
* Alternate Forms
*** Full Scale I.Q.
**** National Adult Reading Test

† NOTE: An explanation of the timing of the assessments in general is given on pages 54 & 55. The precise timing for each case is provided as part of the case description.

(Table 7.20) indicates some awareness of memory problems and the relative's report largely agreed regarding the type of error, but occurring at greater frequency than C. seemed aware. The CFQ, as rated by C.'s father, particularly depicted him as extremely absent-minded and muddled, while he himself only acknowledged this to a modest degree (Table 7.21).

Psychosocial Profile

As seen in Table 7.23, C. denied experiencing significant anxiety or depression. Nor did he experience any degree of subjective burden resulting from his injury. In contrast, his father's anxiety and depression levels both fell in the borderline range, and he reported experiencing a very severe degree of subjective burden. On the semi-structured interview (Table 7,24), C. reported a number of physical problems, including poor vision, poor balance and dizziness, which made him more dependent on others. He also complained of a number of subjective problems and personality change, but denied being more childish, although this was actually one of his most striking characteristics. In contrast, his parents' report suggested that he underestimated the degree to which the problems existed, although they largely agreed with the problems in memory and behaviour that C. himself reported. They also remarked that C. was no longer the adult that he had been prior to his injury and that his constant inappropriate comments in public places were a continual worry to them, and he did not seem to learn from their advice. They said that, in his present state, there was no possibility that C. could return to his previous role as a husband and father and they anticipated looking after him themselves in the long-term.

Case # 3 (C.H.)

Day to Day Memory Questionnaires

Table 7.20: Everyday Memory Questionnaire*

Assessment #	1	2	3	4
Patient	46(36)	51(40)	27(21)	69(54)
Relative	69(54)	78(61)	81(63)	70(55)
Agreement **	9/14 (64%)	9/15 (60%)	8/15 (53%)	13/15 (87%)

Table 7.21: Cognitive Failures Questionnaire*

Assessment #	1	2	3	4
Patient	8(8)	20(20)	13(13)	27(27)
Relative	21(66)	11(34)	15(47)	19(59)

Psychosocial Data

Table 7.22: Hospital Anxiety and Depression Scale

Assessment #		1	2	3	4
Anxiety	- Patient	9	6	8	12
	- Relative	12	13	15	14
Depression	- Patient	6	4	8	15
	- Relative	9	12	13	14

Table 7.23: Subjective Burden

Assessment #	1	2	3	4
Patient	0	0	0	2
Relative	10	7	8	8

*Figures in parentheses are percentages of total possible score, as questionnaires differ in total number of items.
**% agreement by patient and relative on items endorsed.

Case # 3 (C.H.)

Table 7.24: Problems Reported on Interview

	Pre-treatment		Post-treatment	
	Patient	Relative	Patient	Relative
Vision	+	+	+	+
Taste			+	+
Smell			+	
Balance	+	+	+	+
Dizzy Spells			+	
Epilepsy	+	+	+	+
Tiredness	+	+	+	+
Disturbed Sleep				+
Slowness	+	+	+	+
Tension/Anxiety	+	+	+	+
Impatience	+	+	+	+
Noise Sensitivity	+	+	+	+
Irritability	+	+	+	+
Temper		+	+	+
Speaking	+	+	+	+
Wordfinding			+	+
Concentration	+	+	+	+
Memory	+	+	+	+
Depression			+	+
Childishness		+		+
Moodiness		+	+	+
Personality Change	+	+	+	+
'Not bothered'	+	+	+	+
Disabled/dependent		+	+	+
Supervision		+	+	+
Job Prospects	+	+	+	+
Leisure/Social	+	+	+	+
Sex life	+	+	+	+
Total	17	22	26	26
Agreement*:	**Pre-** 77%		**Post-** 85%	

*Percentage of agreement between patient and relative on problems endorsed on interview questionnaire.

Treatment

C. proved unable to keep a record of his memory failures using checklists, instead tending to use the forms as a way of recording humorous or odd experiences during the week. His father therefore kept the weekly records, but still recorded a very low frequency of memory failures, ranging between 5 and 4 per week, during the baseline period (Table 7.25), due to C. being constantly supervised and prompted by others. Despite this, it was clear on both formal and informal evaluation that C.'s memory deficits were severe and his ability to learn appeared limited. At present, he was completely dependent on his parents for day to day orientation and care and he appeared to have difficulty coping even with the very basic tasks he was give to do at work. It seemed that these problems could be alleviated to some degree, albeit modest, if C. could learn simple mnemonic strategies as a source of information to have at hand, and to help monitor his intentions in a more structured way. C.'s silly, disinhibited behaviour was a second problem to tackle as it not only contributed significantly to the burden shared by his parents but resulted in his opportunity for free movement outside the home. The methods introduced included: Daily Activity Schedule, Daily Diary, Pinboard, CHAT and Stop, Look and Listen!

Introduction of the Daily Activity Schedule resulted in an immediate increase in the number of memory failures per week as reported by C.'s father (Table 7.25). While this was in part due to the task itself and the increased demand that learning a new technique placed on C.'s memory, it also appeared to be due to his parents' increased awareness of what C. was unable to remember of previous events. He had difficulty keeping a complete record (Figure 7.5) and his notes were very concrete. A simplified timetable also

Treatment - Case 3 (C.H.)

Table 7.25: Total number of reported memory failures per week during baseline and training phases as recorded on Memory Checklists

		Week # 1	2	3	4	5	6	7
Memory Failures	Baseline (Rel)*	5	4	4	4	4	5	
	Treatment (Rel)	14	14	14	0	6	5	3
	Follow-up (Rel)	26	14					

* Patient unable to recall any failures.

DAILY ACTIVITY SCHEDULE

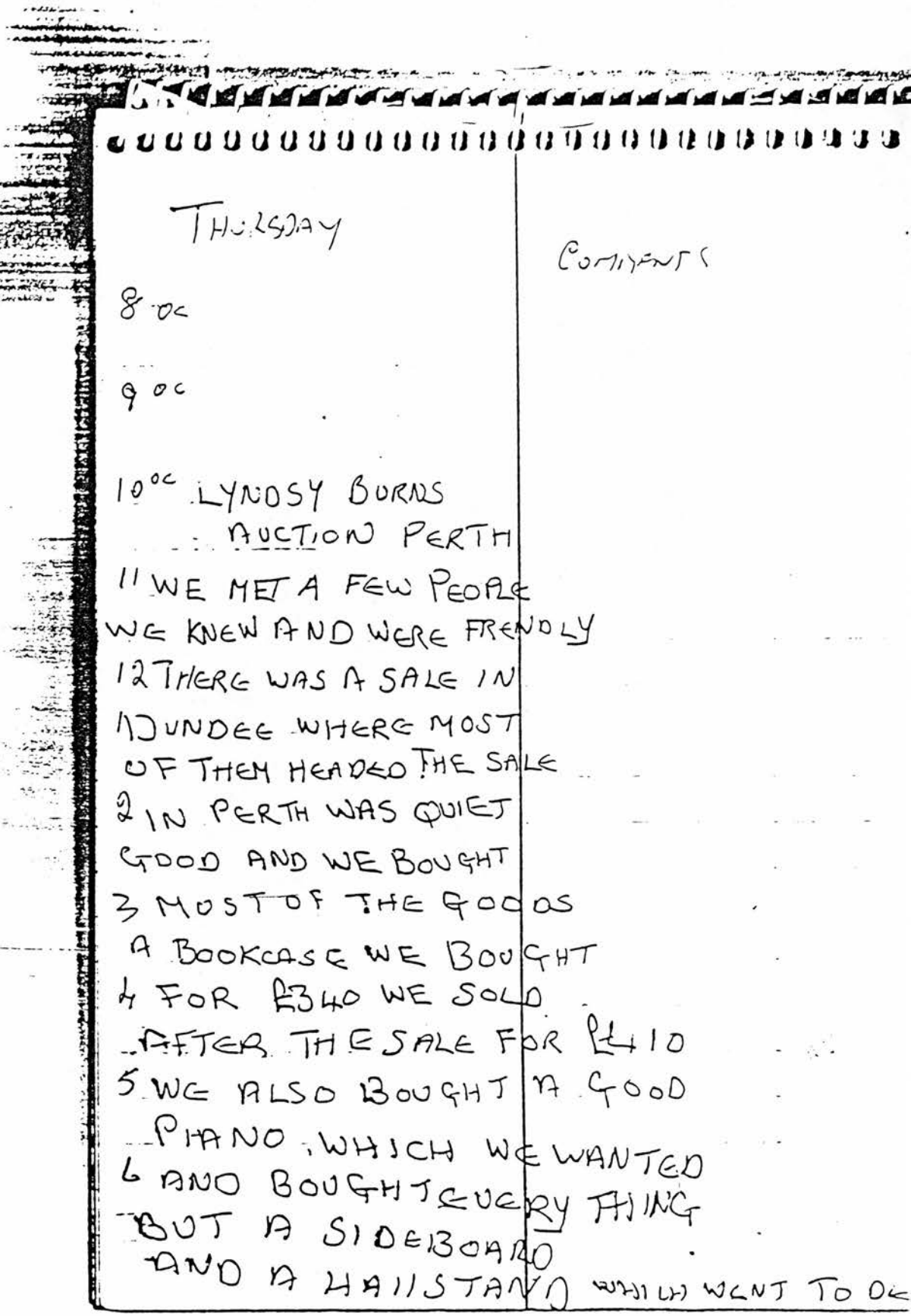
WEEK OF 20/3/87

Figure 7.5: Example of C.H's D.A.S.

	8-9	9-10	10-11	11-12	12-1	1-2	2-3	3-4	4-5	5-6	6-7	7-8	8-9	9-10	10-11
MON DATE:___		TABLETS BATH	WALK WITH DAD	LUNCH UNTIL 2		WALK		BEECH	APART MENT BATH	WALK		BED TABLETS			
TUES DATE:___		TABLETS BATH	WALK WITH DAD	MARKET		APART	BATH SLEEP			WALK		SWOOL	BED TABLETS		
WED DATE:___		TABLETS BATH	SHOP	MARKET	BEECH		LEECRM WITH LISA	AM HOME 5PAM	BED	CARDS WALK		WALK SPOT LOST	HOME TABLETS BED	— —	
THURS DATE:___		BLED BATH	WALK	BEECH UNTL ONE.		WALK	BED	BEECH CARDS	BED	WALK		WALK CARDS	TABLETS BED.		
FRI DATE:___		BATH CARDS	BED TABLETS WALK	FED FISH CARD	— — —	WALK LESA DAD BEECH	WALK SHPS		BED		WALK POOL	WALK POOL	TODDIES BED.		
SAT DATE:___		TABLETS BATH	LUNCH MONEY BANK COFFEE	SHOPPING	BEECH CATCH FISH LESA CABES	BALL HATS BEECH	PICNIC CARDS	LESA BEECH PICNIC	BED	WALK	SNACKS WALK	CAFE LEECRM	WALK	HOUSE TABLETS BED,	
SUN DATE:___		BATH TABLETS	MARKET SPAIN MARKET CLOSED		12.30 SWIM W LESA IN POOL	WALK	BEECH	BED.	BEECH	WAVS	BED	WALK	POOL WITH LESA	WACK LESA ICECRM	BED TABLETS

KEY:

Figure 7.6: Example of C.H.'s Modified D.H.S.



THURSDAY

COMMENTS

8 OC

9 OC

10 OC LYNDSY BURNS
AUCTION PERTH
11 WE MET A FEW PEOPLE
WE KNEW AND WERE FRENDLY
12 THERE WAS A SALE IN
1 DUNDEE WHERE MOST
OF THEM HEADED THE SALE
2 IN PERTH WAS QUIET
GOOD AND WE BOUGHT
3 MOST OF THE GOODS
A BOOKCASE WE BOUGHT
4 FOR £340 WE SOLD
AFTER THE SALE FOR £410
5 WE ALSO BOUGHT A GOOD
PIANO WHICH WE WANTED
6 AND BOUGHT EVERY THING
BUT A SIDEBOARD
AND A HALLSTAND WHICH WE WENT TO OC

proved unweildy for him (Figure 7.6). By the fourth session, when C. was using all three mnemonic strategies, the frequency of memory failure fell. However, it was clear during the sessions that if left to his own devices, C. would not be using the strategies at all, partly because of his failure to remember to use them and partly because of a lack of motivation. Rather, it was only by his parents' constant prompting and steering of C. to use the strategies that any benefit occurred at all. This was thus an extension of their already intense supervision of C., and involved no visible effort on his part. During the latter half of C.'s treatment phase, two social skills exercises were introduced, aimed at 1) improving C.'s interpersonal communication by using the DAS as a source of information during discourse and 2) reducing his tendency to interrupt and make inappropriate comments. Initially, C. appeared to view the exercise as an opportunity to perform for others, increasing the very behaviours which were being tackled. After three sessions which involved consistent, positive feedback, some improvement in his tendency to interrupt was apparent. However, this was limited specifically to the clinical setting and no generalization was evident in other situations. C's treatment ended after seven sessions, as his family planned to travel to the U.S.A. for business purposes.

Post-Treatment

When C. was seen for follow-up on his return, he was no longer using any of the memory strategies and his behaviour appeared no different that it had been prior to treatment. His parents recorded a further increase in the number of memory failures (Table 7.25), which again appeared to indicate a greater insight on their part rather than an increased demand being placed on C.'s memory capacity. On

the Everyday Memory Questionnaire, C.'s increased score suggests a slight increase in his awareness of his memory problems, while his father's rating remained largely unchanged (Table 7.20). There was closer agreement between them on the nature of the memory problems. C.'s increased CFQ score (Table 7.21) also suggested increased awareness, but this fluctuated considerably over the four assessments and remained quite low throughout. His father's CFQ score was largely unchanged. Neuropsychological assessment indicated no frank changes in C.'s overall cognitive status (Table 7.19).

Similarly, psychosocial measures showed no signs of improvement. Both C. and his father reported higher levels of anxiety and depression compared to their pre-treatment levels, now falling within the clinical range (Table 7.22). C.'s reported a very mild degree of subjective burden, while his father's remained severe (Table 7.23). On interview, problems reported at follow-up (Table 7.24) were largely the same as those existing prior to treatment, although again, C.'s report suggested a slightly increased awareness. Overall, C. showed no improvement on any of the measures at the end of treatment. There is consistent evidence of a slight improvement in his self-awareness.

Case # 4 (B.K.)

Demographic and Family Setting

B.K. was a 48 year-old man who sustained an extremely severe head injury when he fell 30 feet while at his job as a boilermaker four years prior to entering the rehabilitation programme. His period of post-traumatic amnesia was at least two months, but he had continued to experience poor orientation since that time (Table 7.2). B. was now unemployed and virtually housebound. His wife, however, had developed an active life outside the home, particularly in activities relating to head injury, e.g. support groups in which he sometimes joined her. B. came across as being very much in his own world, laconic and never initiating conversation or asking questions, automatically relying on his wife to take the lead. His wife presented as a more dominant personality, and was anxious and hesitant about acting as co-therapist. During initial discussion she admitted that she and her husband had not spoken to one another since his head injury, apart from the rarest necessary comments. They had received psychotherapy for this for nearly two years which had ended just before they were referred for the programme. Mrs K. admitted that her reluctance to enter the programme was her fear that pressure would be put on her to speak to her husband. It was agreed that as long as she attended and co-operated as co-therapist, no extra pressure would be put on her, although it was hoped that the communication problems would resolve as treatment progressed. B. and his wife had four children, three of whom lived at home and would be kept informed by Mrs K. about the purpose of the memory programme.

Case # 4 (B.K.)

Table 7.26: Neuropsychological Data for Case # 4

	Assessment #† 1	2	3	4
Logical Memory*				
Immediate	6	4	3	7
Delayed	2	2	2	5
Paired Associates*				
Easy	6	8	8	8
Hard	0	4	0	1
Total	6	12	8	9
Rey-Osterreith*				
Copy	34	34	36	36
Immediate Recall	19	18	14	23
P.A.S.A.T.				
4 seconds	Not able	26/60	30/60	40/60
2 seconds	to do	not done	12/60	16/60
W.A.I.S.- R.**				
Similarities	10		12	
Arithmetic	5		9	
Digit Span	5		10	
Block Design	10		12	
Digit Symbol	8		10	
F.S.I.Q.***	88		103	
N.A.R.T.****	113			
Boston Naming Test	29/60		57/60	
Word Fluency*	(1)		(2)	
Category	7		7	
Easy letter	11		10	
Hard letter	3		7	
Repetition	100/100		100/100	
Token Test	18/21		21/21	

* Alternate Forms Administered
** Age Scale Scores
*** Full Scale I.Q.
**** National Adult Reading Test

† NOTE: An explanation of the timing of the assessments in general is given on pages 54 & 55. The precise timing for each case is provided as part of the case description.

Neuropsychological Profile

The results of B.K.'s neuropsychological assessments (Table 7.26) indicated significant memory deficits, with particular difficulties in mental tracking and processing information. He also showed problems in naming and word finding which were reflected in his verbal adynamia in conversation. Visuo-perceptual abilities were reasonable as was psychomotor speed.

Day to Day Memory

Table 7.27 displays B.'s self-ratings on the Everyday Memory Questionnaire. These were very high, suggesting that he had good insight into the degree to which he experienced memory failures, despite his inactive and dependent lifestyle. By the end of the baseline period this diminished somewhat suggesting that the task of keeping a baseline record itself had a mnemonic effect. His scores on the Cognitive Failures Questionnaire (Table 7.28) remained stable throughout the baseline period. Mrs K. answers suggested very high degrees of everyday forgetting on both questionnaires, remaining high throughout the baseline period.

Psychosocial Factors

Psychosocial measures indicated that both B. and his wife were under considerable emotional strain. On the Hospital Anxiety and Depression Scale B. reported a significant degree of anxiety, while his wife reported significant depressive symptoms (Table 7.29) at both pre-treatment assessments. Both B. and his wife reported experiencing a high degree of subjective burden as a result of the effects of his head injury (Table 7.30). On interview, both

Case # 4 (B.K.)

Day to Day Memory Questionnaires

Table 7.27:Everyday Memory Questionnaire*

Assessment #	1	2	3	4
Patient	115(90)	95(74)	101(79)	104(81)
Relative	126(98)	121(95)	106(83)	107(84)
Agreement **	16/16 (100%)	16/16 (100%)	15/16 (100%)	16/16 (100%)

Table 7.28:Cognitive Failures Questionnaire*

Assessment #	1	2	3	4
Patient	67(67)	67(67)	49(49)	51(51)
Relative	32(100)	32(100)	23(72)	22(69)

Psychosocial Data

Table 7.29:Hospital Anxiety and Depression Scale

Assessment #		1	2	3	4
Anxiety	- Patient	13	16	7	14
	- Relative	9	13	11	11
Depression	- Patient	8	8	9	9
	- Relative	12	10	7	17

Table 7.30:Subjective Burden

Assessment #	1	2	3	4
Patient	8	8	8	6
Relative	8	8	5	8

*Figures in parentheses are percentages of total possible score, as questionnaires differ in total number of items.
**% agreement by patient and relative on items endorsed.

Case # 4 (B.K.)

Table 7.31: Problems Reported on Interview

	Pre-treatment		Post-treatment	
	Patient	Relative	Patient	Relative
Vision	+	+	+	+
Hearing		+		+
Taste				+
Smell		+	+	+
Balance	+	+	+	+
Dizziness	+	+	+	
Headaches	+	+	+	+
Tiredness	+	+	+	+
Sleep		+		+
Slowness	+	+	+	+
Tension/Anxiety	+	+	+	+
Impatience	+	+	+	+
Noise distressing	+	+	+	+
Irritability	+	+	+	+
Temper	+	+	+	+
Violence	+			+
Speaking	+			+
Wordfinding	+	+	+	+
Understanding	+			+
Concentration	+	+	+	+
Memory	+	+	+	+
Depression	+	+	+	+
Childishness	+	+	+	+
Moodiness	+	+		+
Personality Change	+	+	+	+
'Not bothered'	+	+	+	+
Disabled/dependent	+	+		
Supervision	+	+	+	+
Job Prospects	+	+	+	+
Leisure/social	+	+	+	+
Sex life	+	+	+	+
Total	27	27	23	29

Agreement*: **Pre-** 80% **Post-** 73%

*Percentage of agreement between patient and relative on problems endorsed on interview questionnaire.

patient and relative reported a high number of physical, subjective and behavioural effects of the injury (Table 7.31) and there was close agreement between them regarding both the nature and degree of changes. Mrs K. complained that her husband's personality had changed 'completely' from being humorous, sociable and spontaneous to being quiet, remote and apathetic.

Treatment

During the baseline period B. was a conscientious recorder of his memory failures and although these were numerous he appeared undistressed by the task of keeping daily checklists. Table 7.32 displays the weekly total of memory failures recorded jointly by B. and his wife. These range between 74 and 84. They agreed that the same types of errors were being made repeatedly and particularly occurred with any change of routine or when he tried to do something himself, such as DIY. This caused his wife to feel hemmed in by his forgetfulness and reinforced her tendency to take over.

Treatment aims were initially limited in view of the severity of B.'s memory and learning deficits and his apparent lack of drive. His wife's motivation was also in doubt as she had a tendency to refer to him as if he was absent and to make critical comments about him. She also constantly avoided eye contact with him. However, in view of his insight and the clear risks to their marriage if the situation continued in its present state, treatment was offered in the hope that a joint task might not only help B. at least reduce the severity of his everyday memory problems, but also help bridge the communication gap that lay between them.

Treatment strategies therefore included all four mnemonic

CASE # 4 (B.K.)

Table 7.32:Total number of reported memory failures per week during baseline and training phases as recorded on Memory Checklists

	Week #	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Baseline (J)		80	74	77	77	81	84	80	79									
Treatment (Pt)		75	70	51	49	34	26	27	25	33	30	32	27	30	35	24	22	23
(Rel)		81	80	67	60	47	34	38	41	40	(no record made)					32	35	33
Follow Up (Pt)		23	21															
(Rel)		33	36															

Table 7.33:Patient's Self-Rating of Successful Recall of Material Studied using the 'PQRST' Method (10 = good, 0 = poor)

		1	2	3	4	5	6	7	8	9	10	11	12	13
# Recorded	Baseline (½ hour)	2	2											
by patient	(1 hour)	0	0											
	(24 hours)	0	0											
	Treatment (½ hour)	7.2	6.0	6.7	6.3	7.7	7.9	8.0	7.6	8.0	7.3	7.5	7.3	6.7
	(1 hour)	4.3	2.0	3.0	2.5	4.9	2.9	5.3	4.4	5.4	4.1	5.2	4.2	4.8
	(24 hours)	0.2	0	0.2	0.8	1.3	1.6	1.8	1.1	3.0	1.1	1.2	1.4	1.5
	Follow Up (½ hour)	8.3	7.9											
	(1 hour)	5.3	5.7											
	(24 hours)	1.8	1.3											

strategies. In addition, both partners were taught relaxation and latterly social skills strategies, including CHAT and ACT. It was anticipated that, although Social Skills Training would be introduced in the latter part of treatment, efforts to improve the couple's communication would be made throughout the treatment phase in order for there to be any chance of achieving generalization, as it was feared that Mrs K.'s verbal agreement to cooperate might not extend to the prompting and cueing and encouragement that would be required outside the clinical setting.

The first three mnemonic strategies were introduced to B. in the standard way. With his first introduction to the DAS, he reported that it helped him recall what he had done, for example, remember a few details of his weekly art class for which he usually had no memory at all (see Figure 7.7). His wife reported that she found it useful for recall as well. However, his DAS did have blanks in it, occurring when he failed to make a record immediately, and even several hours later could not recall what the had done in order to fill it in. He also tended to use generalities, e.g. writing 'visiting' instead of providing more specific information which would later serve as cues for recall. It was clear that Mrs K. had not been providing the missing information for him and although she was encouraged not to give him too much help, it was emphasized that, at least initially, some cueing and reminding would still be necessary. The Daily Diary was adopted by B. quickly and became a matter of habit, much in the same way that his use of the MCL's was part of his routine. Although the Pinboard was introduced as a strategy, it was some time before Mrs K. felt able to actually unwrap it and put it up, as if she was uncomfortable with such a public display of memory failure. Problems with the DAS continued and included omissions and lack of detail, as well as forgetting to look at it even

#4

WEEK OF 19th. Oct. until 25th Oct '87.

DAILY ACTIVITY SCHEDULE

Figure 7.7: Example of B.K.'s D.A.S.

	8-9	9-10	10-11	11.12	12-1	1-2	2-3	3-4	4-5	5-6	6-7	7-8	8-9	9-10	10-11
MON. 19th.	H.	XV (H)	DAS. & diary.	[R]N.	SQT. children	[TV] news	PQRST.	[R]N. Diary.	Sorting out.	TV	Art class. at Oil on Acrylic starts	Wood and Sug Village	YMCA	XV [R]N X	[TV]
TUES. 20th.	H.	XV (H)	Working on radio.		SQT. with Children	[TV] news. Radio.	XV Diary. [R]N.								
WEDS. 21st	H.	XV (H)	(H)	[R]N.	Edinburgh	At the	X Headway Cafe.		Arndale	PQRST.	[TV] news.	[R]N.	[TV]	XV TV	Diary [illegible]
THURS. 22nd.	SQT. with Brie.	XV (H)	(H) Listen Music	PQRST. paint	SQT. lunch.	BBQ.	XV Frame	Frame. [R]N.	[R]N.	TV	[TV] news.	Mens Fellowship Panel Evening Questions.		XV SQT DAS & MCL	[TV]
FRI. 23rd.		XV (H)	(H) Painting Frame - [R]N.		[TV]	Varnish Decorate frame	XV PQRST.	Watching television	Racing				[TV]	XV TV	
SAT. 24th.	H	XV (H)	Headway at Church Hall, Dalkeith. Frame again.	S.Q.T.	SQT.		XV [R]N	Shopping Centre.			(H) PQRST.	Videos		XV Videos	
SUN. 25th.	H	XV Dress & [illegible]	To Church.	Church. Boys Brigade Parade.		(H)	X SQT.	The Vanishing Act (video)			PQRST.	DAS & MCL Interview	[TV]	XV [R]N.	[R] TV

PLEASE RECORD BRIEFLY THE ACTIVITY CARRIED OUT AT A PARTICULAR TIME (E.G LUNCH, HAVING VISITORS, USING COMPUTER, RESTING ETC).
TRY TO NOTE IT AS PROMPTLY AS POSSIBLE.

X - pill — H - asleep. (H) - helping in house. [R]N - reading newspaper. - travelling. SQT - sitting & talking.

when it was right before him. This was consistent with other persisting memory failures involving misplacing or overlooking objects. A few ad hoc strategies were developed, such as using a neck chain for his glasses, keeping a list of routine places where frequently used objects were kept, and jangling his pockets for keys, etc. when about to leave the house. Finally the Pinboard was put up on the wall facing B.'s bed so that it was the first thing he saw in the morning and he could begin to use his DAS immediately. The rest of the family immediately began to contribute information to it. Both B. and his wife agreed that if the DAS was used regularly there was a big improvement in his ability to remember, but his wife admitted to now always prompting him because she 'couldn't be bothered'. This period of latency, while the techniques took getting used to lasted approximately four weeks and was followed by a phase of greater success and consolidation, reflected in his Memory Checklist weekly totals (Table 7.32). After week six, no particular decrease of forgetting was evident.

P.Q.R.S.T. was not initially considered because of the severity of B.K.'s memory problems and because of the extra work and pressure this might put on their fragile agreement to treatment. However, this was in fact later included, as B.K. continued to complain that his concentration was very poor when reading. A two week baseline indicated minimal recall of material read yet B.K. proved to be a surprisingly assiduous P.Q.R.S.T. student, scheduling his readings in his DAS and carrying out the steps slowly and carefully (Table 7.32). Introduction to the method resulted in immediate improvement in recall, as rated by B.K., although his wife could not confirm this, remaining uninvolved in this strategy. As with the other strategies, B.K. seemed to enjoy the ritual of putting aside time to work at an

exercise. Unlike others using this method, he did not have the benefit of any prompting from his wife but instead used his DAS and Pinboard to remind and test himself. As his success with this proceeded, B. moved on to magazine articles and occasionally attempted to read a book, but found this put too much strain on long-term recall.

At this point in treatment, his progress was better than had originally been expected in his regular use of the strategies, and his apparent benefit from them. As if sensing that his good progress might herald a gradual end to treatment his wife raised the subject of their continuing poor communication and her concerns that this might impede his future progress. Given the opportunity to talk without B. present, she expressed fear of appearing unhelpful because of her reluctance to be involved and admitted that they still did not communicate at all, even to say good morning. Her attitude was very ambivalent. While she found it intolerable to think of this situation going on forever she felt unable to do anything about it, saying 'Maybe if he made the first move'. She had no idea how B. himself felt about the situation, describing him as 'in his own little world' which she was unable or unwilling to penetrate. She saw his silence as a wilful rejection of her and that he was not trying.

This issue became the next focus for treatment. A discussion followed regarding the role of his head injury to B.'s lack of initiative and the role her behaviour had in reinforcing this behaviour. It was pointed out that he had clearly made great efforts throughout treatment to utilize the strategies and it seemed likely that he would make a similar effort once he was made aware of the importance of communication as part of his rehabilitation process. During the discussion further anxieties surfaced which suggested

that, to Mrs K., to begin communicating with B. would lead to more difficult issues about their sexual relationship and other role changes, which she felt unable to handle. Role play exercises were introduced involving very basic communication skills which both found difficult. Following this, B. began to take some initiative in communicating with his wife and expressing some interest in her outside activities. However, she didn't respond to his comments or greetings and felt he was 'intruding' into what she saw as her life. She expressed ambivalence about continuing treatment and her main driving force to continue seemed to be the guilt she experienced because of her unwillingness to cooperate. B. had demonstrated that he could change and this put more pressure on her to reciprocate. At the next session she reported that he had moved back into their bedroom yet they had no discussion about this despite its importance. B. had begun speaking to her on a regular basis yet she still would not answer. B. himself was visibly more cheerful and spontaneous in discussion, describing his continuing success with his mnemonic strategies and his efforts to revive his habit of reading at bedtime and other activities he had enjoyed before his injury. He did not appear too concerned or aware of the emotional turmoil his wife was experiencing. At the next session however, he appeared disheartened and pessimistic. Although his wife now sometimes answered him and would now call him to dinner they did not converse and he found it unsatisfying and a lot of work. They were planning to go on holiday to Spain and he was prepared for his memory to lead to problems and had planned for himself a set of strategies for dealing with any eventuality. On their return they reported that they had lapsed back into not communicating. Mrs K. expressed annoyance at B.'s passivity and his failure to express his wishes, although she admitted giving him no encouragement to do so. She reported feeling that she was punishing him, yet

continued to feel resentment at his increasing self-reliance.

At their final session both reported that B. was forgetting relatively little and was using his strategies as a matter of habit, although he still felt discouraged at times. B. had recently stopped practising PQRST as it appeared to have become an integral part of his reading strategy and he did not feel the need to do it formally. They reported little change in their communication, and although both expressed hope that this would improve, this appeared unlikely without Mrs K.'s involvement. B. was strongly encouraged to ask for help in regard to memory and forgetting as it seemed without this his ability to maintain his improvement would falter. Mrs K. agreed to try to respond to requests for help.

Post-Treatment

Two months later, B. and his wife reported that things were a lot better. As regards to memory, he was continuing to use his memory aids and although he sometimes lapsed she would prompt him if this happened. He was continuing to use PQRST and reported that he was reading 'non-stop', preferring magazines to books. He was writing things down frequently and regularly as a memory aid but also because he seemed to enjoy his new role as the family diarist. This maintenance of success was reflected in his Memory Checklist Totals which were in line with those at the end of the treatment phase (Table 7.32). Everyday Memory Questionnaires completed by B. and his wife did not reflect the degree of this improvement, clearly because he still forgot many things (Table 7.27) although both Cognitive Failures Questionnaire ratings suggested that he was somewhat less absent-minded by the end of treatment and that

this was maintained at follow-up (Table 7.28).

Psychosocial measures indicated that B.K. was still experiencing significant levels of anxiety and borderline depression, albeit with a temporary drop in anxiety at the end of treatment (Table 7.29). His wife's anxiety levels remained largely unchanged throughout the programme but her depression score increased significantly by the end of treatment. B.'s subjective burden, having remained high at the end of treatment, dropped slightly by follow-up. His wife's score, in parallel with her depression, dropped to moderate by the end of treatment only to return to severe by follow-up (Table 7.30). On interview there was little change in the number of problems reported by either B. or his wife, although he described himself as having improved in temperament, and language (Table 7.31). He had also thrown away his stick!

The most apparent change, however, was not picked up on formal measures, but in their verbal report. The couple were now speaking comfortably with each other and had done so for over a month. This had apparently been triggered off by a silver wedding anniversary when their children treated them to a week's trip to Paris. Once there, B. 'demanded' to share a room with his wife. Since then they talked to each other every day and described the atmosphere at home as relaxed. Mrs K. found that she was now able to discuss things with her husband and both felt they would not accept 'the old ways' any more.

Case # 5 (M.L.)

Demographic and Family Setting

M. was a 25 year-old woman who sustained an extremely severe head injury in a road traffic accident (Table 7.2). She had been working as a civil servant prior to her accident and had been living with her boyfriend not far from her parents' home. Since the accident she had separated from her boyfriend (who had been the driver in the accident) and had no contact from him. After the discharge from hospital she initially lived with her parents but returned to her own flat just prior to commencing rehabilitation. She described her parents as being overprotective but they appeared to share a warm and humorous relationship. She presented as a poised and reserved young woman who took great care in her appearance. She was initially reluctant to join the rehabilitation programme as she did not feel that her memory problems were particularly 'noticeable'. She had just begun to attend a Day Centre which she found depressing because she disliked being 'the odd one out' among people who were obviously physically handicapped. Her main desire was to either return to her old job or else 'stacking boxes in a supermarket' and she saw rehabilitation, including the day centre, as obstacles to this aim. She felt she coped well living on her own and denied any day to day problems.

Her parents presented a very different picture describing M. as experiencing gross memory problems, for example, often forgetting what she had done earlier in the day. Her mother continually phoned her to remind her of upcoming events and her father visited her everyday to check that she had not left gas on, etc. Her parents were ambivalent about her living on her own but said she frequently made excuses to come to their house in the evening and staying over.

Case # 5 (M.L.)

Table 7.34: Neuropsychological Data for Case # 5

	Assessment #†			
	1	2	3	4
Logical Memory*				
Immediate	3	5	4	3
Delayed	0	0	0	0
Paired Associates*				
Easy	6	4	5	5
Hard	0	0	3	0
Total	6	4	8	5
Rey-Osterreith*				
Copy	36	35	36	33
Immediate Recall	11	5	16	14
P.A.S.A.T.				
4 seconds	Not done	56	57	58
2 seconds		28	37	31
W.A.I.S.- R.**				
Similarities	11		14	
Arithmetic	13		13	
Digit Span	9		9	
Block Design	11		14	
Digit Symbol	6		6	
F.S.I.Q.***	100		106	
N.A.R.T.****	116			
Boston Naming Test	50/60		57/60	
Word Fluency*				
Category	16		17	
Easy letter	13		11	
Hard letter	8		5	
Repetition	80/100		80/100	
Token Test	21/21		21/21	

** Age Scale Scores
* Alternate forms
*** Full Scale I.Q.
**** National Adult Reading Test

† NOTE: An explanation of the timing of the assessments in general is given on pages 54 & 55. The precise timing for each case is provided as part of the case description.

Although both parents were equally involved in the rehabilitation effort, M.'s mother was to be the key source of information and co-therapist.

Neuropsychological Profile

On neuropsychological assessment (Table 7.34) M. demonstrated very significant, global memory deficits. She was unable to carry out PASAT at all initially. Intellectually, her reasoning ability was in line with her pre-morbid average level of intelligence. However, tests involving mental tracking and sustained concentration were below the expected range. Some mild word finding difficulty was evident.

Day to Day Memory

As shown in Table 7.35 and 7.36 treatment both M. and her parents listed a number of everyday memory problems on both the EMQ and CFQ prior to treatment, but there was a wide discrepancy between the degree to which M. and her parents viewed these as problematic. At her second assessment M. felt unable to complete the questionnaires, apparently because her increasing insight made this task seem both depressing and unwieldy.

Psychosocial Factors

On the HAD scale both M. and her mother both showed borderline levels of anxiety at the initial assessment, dropping slightly over the baseline period (Table 7.37). M.'s depression score rose markedly during the baseline period, from virtually nil to borderline, while her mother's remained at borderline level. M. reported experiencing a moderate burden due to the effects of the accident, while

Case # 5 (M.L.)

Day to Day Memory Questionnaires

Table 7.35:Everday Memory Questionnaire*

Assessment #	1	2	3	4
Patient	41(32)		25(20)	40(31)
Relative	88(68)	86(67)	82(64)	96(75)
Agreement **	7/13 (54%)	- -	4/13 (31%)	10/15 (66%)

Table 7.36:Cognitive Failures Questionnaire*

Assessment #	1	2	3	4
Patient	24(24)	Nil	11(11)	22(22)
Relative	21(66)	19/59	24(75)	25(78)

Psychosocial Data

Table 7.37:Hospital Anxiety and Depression Scale

Assessment #		1	2	3	4
Anxiety	- Patient	7	4	3	6
	- Relative	8	5	6	1
Depression	- Patient	1	8	2	2
	- Relative	6	8	2	3

Table 7.38 :Subjective Burden

Assessment #	1	2	3	4
Patient	5	5	5	3
Relative	8	8	4	6

*Figures in parentheses are percentages of total possible score, as questionnaires differ in total number of items.
**% agreement by patient and relative on items endorsed.

Case # 5 (M.L.)

Table 7.39: Problems Reported on Interview

	Pre-treatment		Post-treatment	
	Patient	Relative	Patient	Relative
Vision	+	+	+	+
Taste				+
Balance	+	+	+	+
Dizzy		+		+
Tired	+	+	+	+
Slowness	+	+	+	+
Tension/Anxiety				+
Impatience		+	+	+
Noise distressing		+	+	+
Irritability		+		+
Temper		+		+
Violence				+
Speaking			+	
Wordfinding		+		+
Understanding				+
Concentration	+	+	+	+
Memory	+	+	+	+
Depression				+
Childishness		+		+
Moodiness				+
Personality change		+	+	+
'Not bothered'		+		+
Disabled/dependent			+	+
Supervision		+		+
Job prospects	+	+	+	+
Leisure/Social	+	+	+	+
Total	8	18	13	25
Agreement*:	**Pre-** 31%		**Post-** 46%	

*Percentage of agreement between patient and relative on problems endorsed on interview questionnaire.

her mother's was more severe. both of their ratings remained unchanged at the end of the baseline phase (Table 7.38). M.'s apparent tendency to play down her problems was apparent in the discrepancy between their reports of problems on interview (Table 7.39). M. acknowledged that her memory and concentration were 'rather' worse but focused on physical problems and denied any subjective stress or behavioural changes. In contrast, her mother reported that M. had changed emotionally and behaviourally and was more dependent than before.

Treatment

Memory Checklists kept by M. herself over the 8 week baseline period, initially showed a very low report of forgetting of around 15 per week although this in itself was the effect of forgetting to fill out checklists. As more foolproof means of keeping the checklist were devised and as M. began to acknowledge the extent to which her memory was a problem, the frequency of forgetting soared. After a few weeks this eventually settled to a range of 85 to 103 recorded episodes of forgetting per week (Table 7.40).

The plan for M.'s treatment included introduction of all five mnemonic strategies with a view to gaining the cooperation of staff at her day centre in backing this up. It was anticipated that, in order to be acceptable to M., the techniques would have to be offered to M. as being similar to social diaries, work timetables etc., while at the same time, helping her to develop insight into the impact her memory deficit would have on her employment prospects and the need for continuing rehabilitation for the foreseeable future. In view of M.'s highly developed social skills no formal plan was made to introduce work in this area. However, it was anticipated that she might have

CASE # 5 (M.L.)

Table 7.40:Total number of reported memory failures per week during baseline and training phases as recorded on the Memory Checklist

		Week #	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22
MEMORY	Baseline (Pt)‡		15	24	113	66	94	85	102	96														
FAILURES	Treatment (Pt)		99	90	78	103	96	102	77	88	39	38	53	28	11	15	10	0	0	0	0	0	0	0
	Follow Up (Pt)		26	31																				

‡ Patient living on own ‡PQRST abandoned, unable to record independently

WEEK OF 5th February

DAILY ACTIVITY SCHEDULE

Figure 7.8: Example of M.L.'s D.A.S.

	8-9	9-10	10-11	11.12	12-1	1-2	2-3	3-4	4-5	5-6	6-7	7-8	8-9	9-10	10-11
MON.		Up Have			Drive to Leeds for knitting	LUNCH TEA WITH	MUM	READ THE SCOTSMAN	TIDYING MRS D'S LOUNGE	WITH MUM	CLEANED + JOHN VISITED	CHINESE CARRY OUT	TV MAGGIE	LATE KNITTING	
TUES.					DANY VISITED TO GET LIFT	WASH UP									KNIT
WEDS.				TV		WASHING UP				SET TABLE					
THURS.							MORE?			TV		TV	TV	TV	
FRI.			TV		LUNCH PLUCAS	PARTY - DANY			SAFEWAY WITH MUM	LEETH TO GET KNITTING + CLOTHES		HELEN VISITED			
SAT.		Up with dad	helping mum	make Dany to gyle	Norha Gordon for lunch			wash up		Up		ELAINE JOIN TO GET ME	TV		
SUN.		Up	clear living room + Dad	Dust Up		Up TV	TV RUGBY	out with D+Rab for a gas cylinder	Go my flat for clothes	my washing in Party	Susie arrived	Hanging with Susie	More Hanging With Susie	TV MTD Up	Bacon + Eggs

PLEASE RECORD BRIEFLY THE ACTIVITY CARRIED OUT AT A PARTICULAR TIME (E.G LUNCH, HAVING VISITORS, USING COMPUTER, RESTING ETC).
TRY TO NOTE IT AS PROMPTLY AS POSSIBLE.

difficulty admitting memory failure on occasion and some help would be offered in this regard if problems arose. It seemed clear that M. wished to appear to be coping independently, but her obvious dependence on her parents and avoidance of challenging situations were anticipated obstacles to goal-setting.

The D.A.S. was introduced and initially accepted by M. without any resistance, although she refused to use pictograms or use red ink for planning as these ideas seemed childish to her (Figure 7.8). As she was staying at her parents most of the time at this point, they were able to prompt her to use it, although this was not often necessary. Although her father felt that, through the DAS, she was beginning to remember much better, he had tried to test her recall for the previous evening's birthday celebration for her and saw that she 'drew a blank!', and did not respond to any cues until she looked at her DAS. The Daily Diary was introduced, although M. complained that there was too much paperwork which she did not like carrying in public. Similarly, the Pinboard remained undisplayed, although many other reasons were given for this, e.g. no nails, no hammer, need father to do it etc. Over the next two sessions this problem began to affect her successful use of the methods as she began to leave the DAS at home rather than risk anyone other than her family seeing it and she began to put unmanageable amounts of information on her Daily diary. It was therefore suggested that she adapt a Filofax (bought for her by her father) to incorporate the information from the DAS and Daily Diary. This suited M.'s need for socially acceptable mnemonic strategies and fitted her undented self-image as a career woman, and she became much more reliable in checking it. She dismissed her father's offer to buy her a clock that bleeped to remind her to check it because she considered this would make her seem 'like a robot'.

Although it was stressed to her that such a device was used by very busy, professional people, she remained adamant. This period of resistance is clearly demonstrated in Table 7.4, which shows a high frequency of forgetting over the first eight weeks of treatment. By week nine her adapted use of the strategies had become established and the number of memory failures continued to decline over the remainder of the treatment phase, finally reaching as low as ten per week.

M. was a reluctant and erratic attender of the day centre, tending to sleep late, or finding the weather too cold. She appeared to contradict herself, complaining that she wasn't given enough independence, yet was not given any help to do the things she found difficult, such as typing. She joined a stroke group at the centre 'as a helper', which involved memory for current events. PQRST was introduced with a view to helping M. with this, but despite her initial interest and expressed wish to read again, she was unable to maintain the task for any length of time, finding the aim of remembering a single article to be 'too limited'. Efforts were made to try to adapt the strategy to her typing skills but she criticised it as making the task of learning to type even slower, feeling that if she only had some proper supervision, she could learn to type quickly, and then return to full-time work. In general she felt the centre was a barrier to her progress and resented going there. Yet when left to her own devices, M. showed little initiative in resuming a social life or going out of her flat at all. These issues were discussed with M. and her mother over the latter part of the treatment phase, and her feelings conveyed to the day centre staff. While M.'s denial seemed a major factor in her reluctance to accept intermediate goals, her need to preserve her self-esteem had to be accommodated in the rehabilitation process. Confronting her

directly would have risked losing her cooperation and triggering depression.

In the last stage of treatment, M. was using the mnemonic strategies well, and without self-consciousness, having adapted them to her Filofax. Her day centre schedule had been altered to resemble a part-time job and she was expected to commit herself to attending as if it were. She was travelling to the centre by bus nearly every day, although some days her father gave her a lift. She had begun to do a little part-time work clearing out flats for an estate agency which she enjoyed and she commented that she no longer wanted a job as a typist. M. was encouraged to find out about special college courses in order to have an aim beyond the day centre, which would hopefully help her have a clearer idea of work opportunities.

Post-Treatment

At the end of treatment M. was experiencing few memory failures. At two months follow-up this number had increased (Table 7.34), although was still nowhere near the level at the commencement of treatment. This indication of relapse was reflected in memory questionnaires. Her Everyday Memory Questionnaire score showed a moderate reduction by the end of treatment, but at follow-up had returned to her pre-treatment level (Table 7.35). Her mother's score, having held steady over the treatment period, was also elevated at follow-up. there was, however, greater agreement between them about the types of errors made. M.'s score on the CFQ (Table 7.36) showed a similar pattern as the first measure, dipping at the end of treatment to a low rate of cognitive failure, but rising to pre-baseline levels at follow-up. Her mother's score, rose over the treatment period and was higher than that at the beginning of the baseline period.

Neuropsychological assessment showed persisting, significant global memory problems (Table 7.34).

Psychosocial measures show that M.'s anxiety level dropped over the treatment phase, but returned at follow up to its borderline, pre-baseline level. Her depression, having risen just prior to treatment, appeared to resolve to insignificance, however. Her mother's anxiety and depression scores, however, having approached the clinical level prior to baseline, were also now minimal, suggesting that treatment had a positive effect on the relative's mood (Table 7.37). Subjective burden scores reduced slightly from their initial moderate and severe levels for both M. and her mother, respectively (Table 7.38). On interview, both M. and her mother reported an increase in the problems experienced but there was a wider agreement between them on this occasion. M. reported more subjective problems than she had prior to treatment, and was more ready to acknowledge her dependence on others. Her mother also reported more changes in M.'s emotional state (Table 7.39). This raises the possibility that treatment, by unmasking M.'s memory problems and increasing her insight, also increased her emotional expression.

Case # 6 (G.A.)

Demographic and Family Setting

G. was an 18 year-old man who had sustained an extremely severe head injury in a road traffic accident 18 months prior to entering the rehabilitation programme. His period of post-traumatic amnesia was approximately five weeks (Table 7.2). He had been working as an apprentice joiner at the time of the injury. He lived at home with his mother, who was divorced, and his younger brother. His mother worked part-time as a domestic and the remainder of her time was occupied looking after G.

Neuropsychological Profile

Table 7.41 shows that prior to treatment, G.'s performance on formal memory tests fell roughly in line with his pre-morbid level of ability, estimated to be average. He had more difficulty on tests involving information processing and concentration, however. Intellectual ability was largely intact, although again his ability to concentrate on complex work was below par.

Day to Day Memory

Table 7.42 and 7.43 detail the results of the Everyday Memory Questionnaire and Cognitive Failures Questionnaire. His self-report suggests moderate problems with day to day memory and absent-mindedness, with his mother's scores indicating a greater frequency of forgetting on both measures. There was large agreement between them as to the type of failures made.

Case # 6 (G.A.)

Table 7.41: Neuropsychological Data for Case # 6

	Assessment #†			
	1	2	3	4
Logical Memory*				
Immediate	9	4	7	9
Delayed	9	3	6	8
Paired Associates*				
Easy	5	8	8	8
Hard	2	7	8	7
Total	7	15	16	16
Rey-Osterreith*				
Copy	36	36	36	36
Immediate Recall	23	23	28	24
P.A.S.A.T.				
4 seconds	41/60	49/60	60/60	59/60
2 seconds	18/60	25/60	27/60	27/60
W.A.I.S.- R.**				
Similarities	10		9	
Arithmetic	12		11	
Digit Span	8		9	
Block Design	7		7	
Digit Symbol	7		8	
F.S.I.Q.***	94		94	
N.A.R.T.****	95			
Boston Naming Test	49/60		49/60	
Word Fluency*				
Category	17		13	
Easy letter	18		11	
Hard letter	6		7	
Repetition	100/100		100/100	
Token Test	21/21		21/21	

** Age Scale Scores
* Alternate Forms
*** Full Scale I.Q.
**** National Adult Reading Test

† NOTE: An explanation of the timing of the assessments in general is given on pages 54 & 55. The precise timing for each case is provided as part of the case description.

Case # 6 (G.A.)

Day to Day Memory Questionnaires

Table 7.42:Everyday Memory Questionnaires*

Assessment #	1	2	3	4
Patient	34(27)	23(18)	27(21)	23(18)
Relative	52(41)	29(23)	28(22)	29(23)
Agreement **	8/13 (62%)	8/13 (62%)	8/13 (62%)	9/13 (69%)

Table 7.43:Cognitive Failures Questionnaire*

Assessment #	1	2	3	4
Patient	37(37)	44(44)	36(36)	39(39)
Relative	15(47)	16(50)	15(47)	13(41)

Psychosocial Data

Table 7.44:Hospital Anxiety and Depression Scale

Assessment #		1	2	3	4
Anxiety	- Patient	16	12	7	7
	- Relative	7	6	4	4
Depression	- Patient	5	9	7	6
	- Relative	3	3	4	4

Table 7.45:Subjective Burden

Assessment #	1	2	3	4
Patient	5	6	3	3
Relative	10	7	3	3

*Figures in parentheses are percentages of total possible score, as questionnaires differ in total number of items.
**% agreement by patient and relative on items endorsed.

Psychosocial Factors

Table 7.44 shows the results of the Hospital Anxiety and Depression questionnaires completed by patient and relative. G. reported significant levels of anxiety at both pre-treatment assessments. His depression score rose over the baseline period, reaching the borderline range. Relative scores on both anxiety and depression remained subclinical on both assessments. G. indicated a moderate degree of subjective burden at both assessments (Table 7.45). His mother initially reported a severe degree of burden, which settled to moderate by the end of the baseline period. Table 7.46 shows the problems reported by both patient and relative on the Head Injury Questionnaire. There is a large agreement between the reports by G. and his mother. He suffered from a left hemianopia and some visual neglect when reading, but the overall picture is of a physically independent person experiencing a number of subjective problems involving anxiety and temper, together with problems in memory and concentration. He described himself as temperamental and violent but his mother considered this to be an exaggeration. She described him as having been an extremely gentle, easy-going person prior to his injury, who was now experiencing a lack of social confidence making excuses for not going out with friends. Because of this, together with his memory lapses, he experienced considerable frustration, occasionally expressed by banging doors. She described him as arguing with his younger brother more frequently than before his injury, perhaps resenting the effect his injury had on his prior role as the elder brother.

Treatment

Over the six week baseline period, G. and his mother jointly recorded few memory failures ranging between three and five per week (Table 7.47). His mother explained that this was

Case # 6 (G.A.)

Table 7.46: Problems Reported on Interview

	Pre-treatment		Post-treatment	
	Patient	Relative	Patient	Relative
Vision	+	+	+	+
Taste		+		+
Smell	+	+	+	+
Balance	+	+	+	+
Dizzy	+	+	+	+
Tired		+		+
Slowness		+		+
Tension/Anxiety	+		+	
Impatience	+	+	+	+
Irritability	+		+	
Temper	+	+	+	+
Violence	+		+	
Concentration	+	+	+	+
Memory	+	+	+	+
Childishness		+		+
Moodiness	+		+	
Personality Change	+	+	+	+
'Not bothered'	+	+	+	+
Job Prospects	+	+	+	+
Leisure/Social	+	+	+	+
Sex Life	+	+	+	+
Total	17	17	17	17

Agreement*: **Pre-** 62% **Post-** 62%

*Percentage of agreement between patient and relative on problems endorsed on interview questionnaire.

largely because they already used some memory strategies, such as a pinboard, and the use of the MCL´s had made them even more conscientious in this regard. Both formal and informal memory assessments suggested that G.´s memory problems were modest, but undermined his confidence and contributed to the burden experienced by his mother. The aim of treatment was to systematise their existing use of methods, to make them simple to use and build on these as appropriate. A second aim was to help G. become more confident in social situations and encourage him to become more active outside the home. Strategies introduced therefore included the five main memory strategies as well as some training in social skills, particularly CHAT. With the introduction of the DAS, Daily Diary and Pinboard, G. realized that he had been forgetting details of the previous day which he had not been recording on his MCL´s. He quickly adopted the strategies, using pictograms, and with his mother´s encouragement, was using them regularly very soon after they were introduced. He found that by writing things down he was able to remember without looking at the information later, that is, intending to remember appeared to be an effective mnemonic. Table 7.47 shows that by week eight of treatment no memory failures were recorded by either G. or his mother.

Although he had not been a great reader prior to his injury he had enjoyed motorcycle and sports magazines but now found he was unable to persist with reading articles. PQRST was therefore introduced after a baseline showed moderate ability to retain information. Initially he found this very hard work and his mother also complained that she felt like he was ´back at school´ with her in the role of checking his homework. She was certain he would not practice it unless she kept after him. They were reminded that PQRST was usually a challenge at first, as it was a new system to them

CASE # 6 (G.A.)

Table 7.47:Total number of reported memory failures per week during baseline and training phases as recorded on Memory Checklists

	Week #	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Baseline (J)‡		5	3	4	3	3	3										
Treatment (J)		1	3	2	2	2	2	1	0	0	0	0	0	0	0	0	0
Follow Up (J)		0	0														

Table 7.48:Patient's Self-Rating of Successful Recall of Material Studied using the 'PQRST' Method (10 = good, 0 = poor)

		1	2	3	4	
‡ Recorded by Patient	Baseline (½ hour)	6	5	6	5	
	(1 hour)	6	4	6	6	
	(24 hours)	5	4	4	4	
	Treatment (½ hour)	6.5	6.5	7.0	7.5	7.0
	(1 hour)	6.0	6.0	7.0	7.0	7.5
	(24 hours)	5.0	6.0	6.5	7.0	7.0
	Follow Up (½ hour)	7.5	7.0			
	(1 hour)	7.0	7.5			

‡ Recorded jointly

and placed demands on G.'s concentration but that it was hoped that with practice it would become easier, becoming his responsibility. However, they were advised not to press on if they felt it added too much to existing stress. Table 7.48 shows G.'s PQRST self-ratings indicated slight improvement in retention of information after 24 hours. By the end of the treatment phase G. was reading a newspaper every day and usually self-initiated his PQRST practice without his mother's prompting.

The DAS was used as the basis for focusing on situations where G. experienced particular difficulties coping. It was suggested that he make a list of activities which he used to enjoy prior to his accident and to consider which of these a) he could still do, b) found difficult, c) found impossible.

This highlighted anxieties that he had about his ability to participate in conversations where there was some distraction, e.g. pubs, but also his self-consciousness regarding old friends raising the subject of his head injury. He was afraid that a simple act, such as asking someone to repeat what they had said, would require a long explanation about his head injury and its effects. he also began to experience panic attacks, resulting from a fear that as he became better able to remember events, he might recall the trauma of his accident. His mother reported that she had never had a break from caring for her son since his accident and although she had an opportunity coming up to get away for a few days, she worried about his ability to cope at home, even with his brother staying with him. Relaxation techniques were introduced and followed by a discussion about amnesia. Two video sessions were scheduled, the first using CHAT as a structure for practising basic skills, and the second using ACT for more

Figure 7.9: Example of G.A.'s P.Q.R.S.T. Study Form

P Q R S T STUDY FORMS

PREVIEW Note general content of article. List key words:

COTTAGE FIRE HORROR

QUESTION List up to 4 main questions to be answered:

(1) who

(2) what

(3) where

(4) when

READ

STATE Briefly note recall of material. A woman cried when fire destroyed her cottage in GRETNA the woman was not named. A man who escaped the blaze was treated in hospital for shock

TEST Answer the main questions:

(1) The woman was not named

(2) Fire in her cottage

(3) GRETNA

(4) Yesterday

assertive responses. Figure 7.8 shows an example of his CHAT homework. This was used as the basis of a discussion regarding G.'s need to develop his confidence and sense of self-reliance as well as his mother's need to have some respite from her caring role. Both agreed their relationship had become enmeshed because of his initial dependency needs but that now it was more appropriate for each to have some time and space from the other. At his final appointment G. felt that he was doing well. He was no longer forgetting anything and his mother said he was self-reliant in his use of the mnemonic strategies. She felt he was more confident than he had been before treatment, and he was beginning to take up his previous physical activities and slowly becoming more socially outgoing. He had obtained a place on a residential employment training scheme arranged by Manpower Services which both he and his mother were looking forward to, albeit with some apprehension at their first separation since his accident.

Post-Treatment

Over the final half of the treatment phase no memory failures were recorded on weekly checklists and this success was maintained at two months follow-up (Table 7.47). His modestly improved PQRST scores were also maintained and he was showing more autonomy in practising this regularly (Table 7.48). His moderate scores on the memory questionnaires remained largely unchanged at the end of treatment from those prior to baseline (Tables 7.42 and 7.43). His mother's reports on the questionnaires was largely in line with that at the end of baseline and remained unchanged by follow-up. There continued to be reasonable agreement regarding the nature of the memory problems. Neuropsychological assessment following treatment showed that G.'s ability to learn new material had clearly

improved since his pre-treatment assessments. His other scores remained steady (Table 7.41).

On psychosocial measures G.'s anxiety level fell markedly from the significant level reported at both pre-treatment assessments to subclinical levels at both assessments following treatment (Table 7.44). His depression scores remained insignificant throughout the programme. His mother'sanxiety and depression levels remained largely unchanged throughout, falling below the clinical range. G.'s subjective burden rating showed a slight reduction from his moderate pre-treatment levels (Table 7.45). His mother's rating on this measure, having been very severe initially and dropping somewhat at the end of baseline, now fell well within the mild-moderate range. This very marked reduction in her experience of strain related to her son's injury was reflected in her expressed relief that he had become more independent and appeared to have some possibility of future occupation. Their reports of problems on interview were unchanged from those at the initial assessment and their reasonable agreement was also unchanged (Table 7.46). Thus, despite the persistence of the effects of his head injury, there does so seem to have been some improvement in both G.'s and his mother's emotional states following treatment.

Case # 7 (T.B.)

Demographic and Family Setting

T. was a student at University at the time of his injury, when he was hit by a car while waiting to cross the street. He was 19 years old at the time of the accident. His period of post-traumatic amnesia was extensive, being at least six months with fluctuating amnesic episodes since then (Table 7.2. His period of retrograde amnesia was striking. he had only isolated memories of being at University and his memory for his school days was very patchy, consisting of islands of memory dating back to early adolescence. Just prior to the accident his father had been diagnosed as suffering from Alzheimer's disease and his parents had moved out of the city in order to get away from the stress of living in town while T. remained, living in a student flat. Following his accident his mother bought a small flat in town where they planned to stay while T. convalesced. At the time he entered the rehabilitation programme, 18 months after his accident, T. was still living with his parents in this setting. He was the youngest of five children.

Neuropsychological Profile T.'s assessment results can be seen in Table 7.49. His performance demonstrated that his ability to recall material, although falling largely in the average range, fell significantly below his (at least) high average estimated pre-morbid level of ability. In view of this pre-morbid level, his ability to learn new verbal information was extremely poor. Problems with retrieval particularly seemed to underlie these difficulties. Reasoning ability appeared largely intact. Difficulties in naming and word finding were also evident.

Case # 7 (T.B.)

Table 7.49: Neuropsychological Data for Case # 7

	Assessment # †			
	1	2	3	4
Logical Memory*				
Immediate	12	10	Patient dropped out	
Delayed	9	9	before end of treatment	
Paired Associates*	(A)	(B)		
Easy	8	7		
Hard	4	2		
Total	12	9		
Rey-Osterreith*				
Copy	36	35		
Immediate Recall	22	24		
P.A.S.A.T.				
4 seconds	55/60	59/60		
2 seconds	38/60	37/60		
W.A.I.S.- R.**				
Similarities	13			
Arithmetic	14			
Digit Span	11			
Block Design	14			
Digit Symbol	8			
F.S.I.Q***	110			
N.A.R.T.****	118			
Boston Naming Test	48/60			
Word Fluency*	(1)			
Category	15			
Easy letter	16			
Hard letter	7			
Repetition	100/100			
Token Test	21/21			

* Alternate Forms Administered
** Age Scale Scores
*** Full Scale I.Q.
**** National Adult Reading Test

† NOTE: An explanation of the timing of the assessments in general is given on pages 54 & 55. The precise timing for each case is provided as part of the case description.

Everyday Memory

The results of T. and his mother's EMQ and CFQ ratings can be seen in Tables 7.50 and 7.51. On both questionnaires T. reported both frequent and numerous memory failures. His mother reported these to a lesser degree, particularly on the CFQ, although there was reasonable agreement between them regarding the type of error made. He complained that such questionnaires had no meaning for him, as he forgot 'everything all the times' His mother seemed much less aware that his memory was a problem, probably because of her pre-occupation with her husband's illness and his much more severe memory problems.

Psychosocial Factors

Scores for both anxiety and depression fell in the clinical range for both T. and his mother, and apart from his depression score, also showed some reduction over this period (Table 7.52). Both T. and his mother reported moderately severe subjective burden which diminished slightly over the baseline period (Table 7.53). Both T. and his mother reported few problems on interview (Table 7.54), but there was close agreement between them on what these were. T. described himself as 'a man of extreme leisure - unemployed', indicating a sardonic tone that frequently appeared during his involvement with the programme.

Treatment

Over the baseline period T. reported an extremely high frequency of memory failures using the memory checklists, falling between 88 and 104 failures per week and this remained stable throughout the baseline period (Table 7.55). Despite this T. initially appeared a promising candidate for

Case # 7 (T.B.)

Day to Day Memory Questionnaires

Table 7.50:Everyday Memory Questionnaires*

Assessment #	1	2	3	4
Patient	95	83	NOT	
Relative	70	69	AVAILABLE	
Agreement **	10/16 (63%)	11/15 (73%)		

Table 7.51:Cognitive Failures Questionnaire*

Assessment #	1	2	3	4
Patient	40	42	NOT	
Relative	14	14	AVAILABLE	

Psychosocial Data

Table 7.52:Hospital Anxiety and Depression Scale

Assessment #		1	2	3	4
Anxiety	- Patient	17	14	NOT	
	- Relative	16	14	AVAILABLE	
Depression	- Patient	18	18		
	- Relative	15	13		

Table 7.53:Subjective Burden

Assessment #	1	2	3	4
Patient	8	5	NOT	
Relative	6	5	AVAILABLE	

*Figures in parentheses are percentages of total possible score, as questionnaires differ in total number of items.
**% agreement by patient and relative on items endorsed.

Case # 7 (T.B.)

Table 7.54: Problems Reported on Interview

	Pre-treatment		Post-treatment	
	Patient	Relative	Patient	Relative
Vision		+	Patient dropped out	
Headaches	+	+	during treatment.	
Tiredness	+	+		
Sleep	+	+		
Slowness	+	+		
Tension/Anxiety	+	+		
Wordfinding	+			
Understanding	+			
Concentration	+	+		
Memory	+	+		
'Not bothered	+	+		
Job prospects	+	+		
Leisure/Social	+	+		
Total	12	11		

Agreement*: **Pre-** 77%

*Percentage of agreement between patient and relative on problems endorsed on interview questionnaire.

memory rehabilitation. He was already using a number of mnemonic strategies, including visual imagery, and had been reading popular self-help books on improving memory. However he clearly had very high expectations and seemed eager to act as fellow scientist rather than as a patient needing help and was quick to point out that he intended to return to University, where such techniques might prove helpful for passing exams. Over the baseline period he brought in diaries that he kept at night which showed great difficulty in recalling sequential events and demonstrated a large mismatch between his intentions to record and his actual ability. He began to complain that he was unable to remember his dreams and focused on this as a target for treatment. He had considerable insight into his memory deficits, describing a cloudy trail of amnesia behind him as the day progressed, until by evening he had forgotten virtually everything that had happened that day, except for events he had noted on scraps of paper. He felt he had access to many memories as 'things come out of the blue' and needed a structure to get him out of 'limbo'. He complained that he was unable to sleep at night, waiting to 'wake up and find my memory back'. He expressed feelings of guilt that he was a burden on his mother who was already having great difficulty coping with her husband's increasingly bizarre behaviour and he tried to present a coping image to her.

Treatment aims were modest in view of T.'s gross memory deficits and the need to refrain from imposing any greater stress on his mother. it was agreed that she would attend sessions if and when she was able and T. could convey information and handouts to her during treatment. it appeared that, despite his good insight, T. demonstrated a marked degree of denial by his stated intention to return to University, his search for increasingly more sophisticated

CASE # 7 (T.B.)

Table 7.55:Total number of reported memory failures per week during baseline and training phases as recorded on Memory Checklists.

	Week #	1	2	3	4	5	6	7
MEMORY	Baseline (P)*	104	94	88	88	95	94	92
FAILURES	Treatment (P)	73	68					

* Mother caring for husband with Alzheimer's. Patient dropped out after week 2 of treatment.

mnemonic techniques and his expectations of sudden recovery. It was expected that PQRST would appeal to him, being a study method in its original form. However, before this was introduced, T. would need a basic structure to sequence events and to help him acknowledge the degree to which his deficits put limits on his learning capacity. It was also felt that some social skills training, to reduce his tendency to bluff through situations might be of value later on. It was planned that the five main memory strategies would be introduced to T. and modified as necessary to be made acceptable to him.

At his initial treatment session T. became angry and upset at being introduced to the DAS. He insisted that he was already tired of paper and pencil techniques and needed mental exercises which would help him 'learn lists of names and dates in history'. After a brief discussion about the nature of recovery, together with encouragement regarding the purpose of simple techniques as a means of providing the basis for more elaborate methods, T. agreed to try the DAS out, but insisted he would come back with better ideas. At the next session he had clearly spent some time practising using the DAS but he did not bring it with him. As shown in Table 7.55, his MCL's suggested that he may have benefited modestly from this method. He reported that he had given the handouts to his mother but had not felt able to ask her to be involved.

In a discussion about how he had found the DAS in practice he became angry saying that he was not 'yet' as badly off as his father and therefore would not need it. What he wanted, he said, was to work with a computer which, being like a brain itself, would be a far more sensible use of his time. At this point it seemed that persisting with treatment would add to the stress of the family and that T. was not ready to

accept compensatory memory strategies and intermediate goals. It was felt that further treatment along these lines could result in further loss of self esteem and deepen his depression. These issues were discussed with T.B who chose not to continue treatment and expressed great relief at his decision. Following this, it was arranged for him to enter a programme of research being carried out by another neuropsychologist which involved computer training for attentional deficits. T. looked forward to this prospect, from which it seemed that he might be able to accept negative results, if this occurred. (It later emerged that he left this programme discouraged but undaunted in his search for remedial methods).

Case # 8 (P.C.)

Demographic and Family Setting

P. was 21 years old when she entered the rehabilitation programme, nine months after sustaining an extremely severe head injury in a road traffic accident (Table 7.2). Her period of post-traumatic amnesia was approximately one month and her retrograde amnesia extended over a year prior to the accident. She had virtually no memory of her previous job as a sewing machinist in a small factory. She was the youngest of four children and the only one still living at home. At the time of the accident she had been engaged to be married and wedding plans had been made. Since the accident her fiance had tried to retrieve the relationship but P. had no consistent memory of him and no feelings for him except for sympathy. There was a history of mental breakdown in the family. Her mother had suffered two breakdowns in the past and was currently being treated for anxiety by her G.P. P. had a brother who suffered from schizophrenia and whose condition was fluctuating at the time of her accident. She was attending a Day Centre at the time of entering rehabilitation.

Neuropsychological Profile

Formal memory assessment indicated significant problems in verbal memory and new learning (Table 7.56). Difficulties in immediate attention span and information processing were also evident. Visual memory appeared intact. Intellectual ability was below expected, in view of her estimated average pre-morbid level. P. also showed problems in word finding and naming.

Case # 8 (P.C.)

Table 7.56: Neuropsychological Data for Case # 8

	Assessment #†			
	1	2	3	4
Logical Memory*				
Immediate	4	3	11	Not
Delayed	3	2	8	Done
Paired Associates*				
Easy	8	6	8	
Hard	3	1	4	
Total	11	7	12	
Rey-Osterreith*				
Copy	35	36	35	
Immediate Recall	27	27	30	
P.A.S.A.T.				
4 seconds	38/60	41/60	45/60	
2 seconds	15/60	23/60	30/60	
W.A.I.S.- R.**				
Similarities	7			
Arithmetic	8			
Digit Span	6			
Block Design	8			
Digit Symbol	8			
F.S.I.Q.***	107			
N.A.R.T.****	107			
Boston Naming Test	34/60			
Word Fluency*	(1)			
Category	15			
Easy letter	16			
Hard letter	8			
Repetition	100/100			
Token Test	17/21			

** Age Scale Scores
* Alternate Forms
*** Full Scale I.Q.
**** National Adult Reading Test

† NOTE: An explanation of the timing of the assessments in general is given on pages 54 & 55. The precise timing for each case is provided as part of the case description.

Day to Day Memory

Both P. and her mother reported a high frequency of day to day memory failures and absentmindedness on the EMQ and CFQ persisting throughout the baseline period (Tables 7.57 and 7.58), and her mother's rating showed an increase on both measures by the end of the baseline.

Psychosocial Factors

P.'s scores for both anxiety and depression rose from the borderline to the clinical range by the end of the baseline. Relative scores remained subclinical on both measures (Table 7.59). A severe degree of subjective burden was experienced by both P. and her mother throughout the baseline period (Table 7.60). On interview (Table 7.61), P. considered her main problems to be her lack of confidence and felt frustration at her difficulty in expressing herself. She found herself feeling anxious and panicky and was phobic about riding on public transport. Her mother felt that P.'s memory and temper problems were severe and interrelated and she felt that P. lacked insight into both of these problems, describing her as being more like a twelve year-old.

Treatment

Baseline records were kept for both memory failures and temper outbursts* and although treatment was aimed at both of these problems, primarily memory will be discussed here. Given the degree of urgency regarding temper, it seemed very unlikely that would cooperate with memory techniques while so highly stressed. Therefore treatment was initially aimed

* P.'s temper data can be seen in the Appendix.

Case # 8 (P.C)

Day to Day Memory Questionnaires

Table 7.57:Everyday Memory Questionnaire*

Assessment #	1	2	3	4
Patient	89(70)	98(76)	24(19)	Not
Relative	91(71)	124(96)	78(61)	Available
Agreement **	15/16 (94%)	16/16 (100%)	9/17 (56%)	

Table 7.58:Cognitive Failures Questionnaire*

Assessment #	1	2	3	4
Patient	42(42)	84(84)	19(19)	Not
Relative	22(69)	30(94)	25(78)	Available

Psychosocial Data

Table 7.59:Hospital Anxiety and Depression Scale

Assessment #		1	2	3	4
Anxiety	- Patient	8	16	6	Not
	- Relative	7	9	4	Available
Depression	- Patient	9	14	0	
	- Relative	3	4	4	

Table 7.60:Subjective Burden

Assessment #	1	2	3	4
Patient	10	10	0	Not
Relative	10	10	8	Available

*Figures in parentheses are percentages of total possible score, as questionnaires differ in total number of items.
**% agreement by patient and relative on items endorsed.

Case # 8 (P.C.)

Problems Reported on Interview

	Pre-treatment		Post-treatment	
	Patient	Relative	Patient	Relative
Vision	+	+	Not Available	
Hearing	+			
Taste	+			
Smell	+	+		
Balance	+	+		
Dizzy	+			
Headaches	+	+		
Tiredness	+	+		
Sleep	+	+		
Slowness	+			
Tension/Anxiety	+	+		
Impatience	+	+		
Noise Distressing	+	+		
Irritability	+	+		
Tmper	+			
Violence	+			
Speaking	+			
Wordfinding	+	+		
Understanding	+			
Concentration	+	+		
Memory	+	+		
Depression	+	+		
Childishness	+	+		
Moodiness	+	+		
Personality Change	+	+		
'Not bothered'	+	+		
Disabled/dependent	+			
Supervision	+	+		
Job prospects		+		
Sex life	+			
Total	29	21		

Agreement*: **Pre-** 61% **Post-** N/A

*Percentage of agreement between patient and relative on problems endorsed on interview questionnaire.

at reducing the frequency of her temper outbursts before introducing mnemonic strategies. Briefly, this involved relaxation training, and a structured approach to identifying triggers to temper outbursts, then implementing alternative behaviours in stressful situations (see Appendix for temper handouts). During this time, her self-awareness and self-confidence improved. During the sessions, her mother tended to speak for her and then to speak about herself and her own emotional needs which she felt were still unmet. By her sixth session P. had had no temper outbursts for two weeks and memory strategies were introduced at this point in treatment. Her baseline record of memory failures per week, recorded jointly, fluctuated initially, but eventually fell between 89 and 132 failures per week (Table 7.62). The strategies involved included the Daily Activity Schedule, Daily diary, Pinboard and CHAT.

The techniques were introduced separately and P. was enthusiastic in her effort to show that she was capable of carrying through the advice. In view of her intact visual memory, she was encouraged to use pictograms to aid her recall, and she was inventive in her application of these (Fig 7.10): Problems occurred if she left the DAS behind when going out and she was reluctant to let her mother prompt her, becoming quickly irritated by this. She seemed eager to show that it was her own work. The Daily Diary helped overcome this problem as she kept it with her at all times, then used it to help her complete the DAS later on. Her success with these two methods, (Table 7.62) made the use of the Pinboard seem almost redundant, but this was offered as an option. The DAS revealed that she had a tendency to fall back on fairly repetitious activities, such as knitting, rather than trying new things. She expressed a curiosity, but lack of confidence, in picking up her previous skill in drawing and painting. She was encouraged

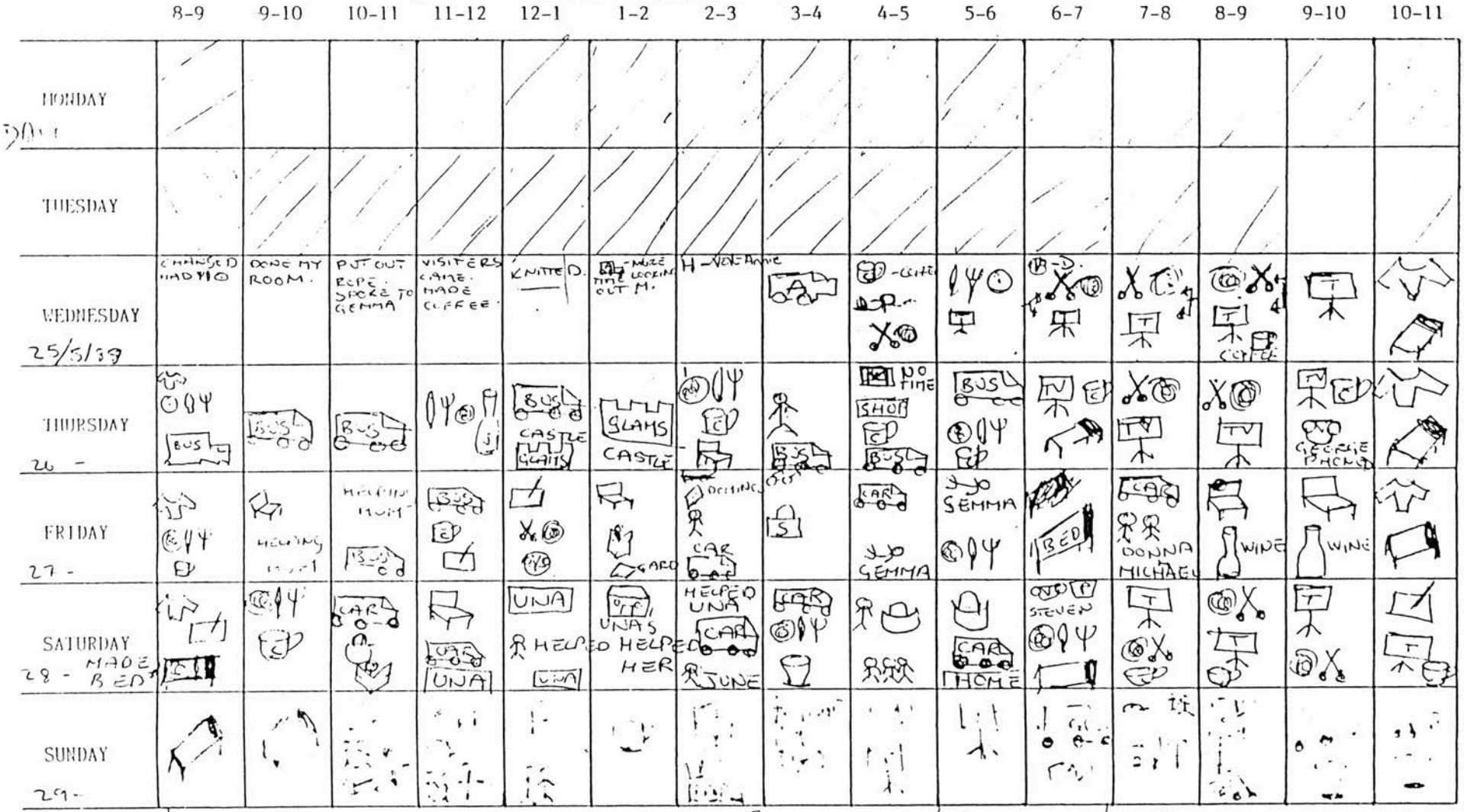
CASE # 8 (P.C.)

Table 7.62:Total number of reported memory failures per week during baseline and training phases as recorded on Memory Checklists

	Week #	1	2	3	4	5	6	7	8
Baseline	(J)	70	128	89	121	132			
Treatment	(J)	19	15	12	8	6	7	8	
Follow Up	(J)	0	0						

DAILY ACTIVITY SCHEDULE

Figure 7.10: Example of P.C.'s D.A.S.



to plan activities which incorporated such neglected interests, and to avoid monotony. She described a 'fight going on in my head' between who she was before the accident and who she was now and repeatedly described herself as completely different. Yet this seemed to rule out a number of things she had been good at before, such as drawing, and she was encouraged to take a less rigid attitude towards recognizing her new identity. She described situations where friends insisted she had not changed, and she felt it was important to emphasise how different she felt inside.

This led to a discussion about interests and abilities she had had prior to the injury and the chance of taking some of these up again. She expressed awareness that she would be unable to study English again because of her poor concentration but did feel that she had potential in non-verbal skills such as drawing and painting. She began to help out others at he Day Centre and this seemed to bring her confidence up to a level where she felt able to attempt drawing again. Social situations with old friends still presented problems due to her poor memory of their shared experiences and her friends' well meaning efforts to reassure her she was 'just the same'. Social skills exercises, based on CHAT, were practised using video, aimed at reducing the amount of information she felt she had to give to others about her injury, and to reduce bluffing when this was not appropriate. On viewing a replay of the tape, she remarked that she appeared much more attractive and articulate than she perceived herself to be and seemed surprised to find that she appeared so normal.

During this time, family crises were occurring. Her father was in hospital for heart problems, a brother in the army had been court-martialled for assault and the brother who suffered from schizophrenia had had a breakdown and was now living at home.

As treatment progressed P.'s mother, while expressing pleasure at her progress, frequently described P. as 'fed up' and 'stubborn', yet P. herself was describing a busy life at the day centre, drawing, typing and 'helping others' and was about to get a part-time job in a home for the elderly. Her mother expressed anxieties about P.'s ability to cope with her increasing independence and expressed a wish to continue looking after her 'until she's better'. P. planned a trip to visit a friend who had also suffered a head injury and was upset when she heard her mother 'make me sound mental' when talking to the friend's mother about her. Her anxieties were reinforced when P. returned from the trip engaged to her friend, exactly one year from the day she would have been married. A week later the engagement was off and P. felt her impulsiveness had been directly due to the feelings of bereavement at her lost relationship. Her mother reported that she herself had 'no tears left'.

At her final treatment session P. was self reliant in her day to day life, although still at home. She continued to experience irritability in some situations but had had no temper outbursts for several weeks. She did not consider her memory to be a problem anymore and now only depended on the Daily Diary and a calendar. Her mother considered that there had been a big change in P. since treatment began, although it seemed that P.'s improvement and subsequent independence left her mother feeling abandoned and unwanted.

Post-Treatment

Due to increased stresses within P.'s family after treatment which were unrelated to her memory rehabilitation, it was not possible to arrange a follow-up assessment. However, she did send in follow-up MCL's. At the end of treatment, P. was forgetting very few things and at follow-up she and

her mother reported that there were no noticeable memory failures (Table 7.62). The improvement in her memory recorded at the end of treatment was also reflected in P.'s memory questionnaires. Her EMQ score was less than a third of her initial score (Table 7.57) and her Cognitive Failures Questionnaire score had halved (Table 7.58), even after the increase that had been seen at the end of the baseline phase. Her mother recorded a much more modest reduction on Everyday Memory and there was less agreement between them as the the nature of the memory problems. Although Mrs C.'s score on the CFQ was lower than it had been just prior to treatment, it had not returned to its pre-baseline level and remained high.

A discrepancy between P.'s perspective and that of her mother was also evident on psychosocial measures. P.'s anxiety, having risen considerably from borderline to the clinical range over the baseline period, had fallen back to borderline at the end of treatment. Her depression score was asymptomatic, having also risen to significance at the end of baseline (Table 7.59). Her mother, however, reported mild anxiety and depressive symptoms at the end of treatment. P.'s burden score, having remained at a very severe degree prior to treatment was non-existent at the end of treatment, while her mother's remained at a severe level throughout the programme (Table 7.60). Unfortunately, the lack of interview data at follow-up makes it impossible to look at other factors which might shed light on this inconsistent picture. It can be supposed, however, that the other family stresses were contributing to Mrs C.'s experience of burden, while P. was more able to focus on her own improvement.

Case # 9 (R.V.)

Demographic and Family Setting

This 40 year-old woman sustained a very severe head injury when she and her husband were struck by a car when crossing a road after an evening of drinking. Her demographic details can be seen in Table 7.2. She entered the rehabilitation programme nine months after her injury. Prior to her injury, she had been occupied bringing up her two teenage children. A few weeks before her initial attendance her husband separated from her because of her violent temper outbursts but he hoped to return to her if her problems improved after rehabilitation. As he worked away from home and was thus unable to take part in rehabilitation her 15 year-old son agreed to act as co-therapist.

Neuropsychological Profile

Only the initial pre-treatment assessment was carried out as her severe temper problems warranted treatment to begin soon after the baseline records were started. The results (Table 7.63) indicated significant global memory deficits as well as difficulty sustaining concentration. Her reasoning ability appeared in line with her estimated average pre-morbid level. She demonstrated some dyspraxia and there was evidence of expressive difficulties.

Day to Day Memory

The results of her day to day memory questionnaires, as shown in Tables 7.64 and 7.65, suggest moderately frequent memory failures and cognitive failures. There was a wide discrepancy between her subjective report and that of her

Case # 9 (R.V.)

Table 7.63: Neuropsychological Data for Case # 9

	Assessment # †			
	1	2	3	4
Logical Memory*				
Immediate	5	NOT	11	11
Delayed	5	DONE	11	6
Paired Associates*				
Easy	8.5	NOT	8.5	8.5
Hard		DONE	1	5
Total	12.5		9.5	13.5
Rey-Osterreith*				
Copy	29	NOT	35	32
Immediate Recall	14	DONE	24	17.5
P.A.S.A.T.				
4 seconds	51/60	NOT	53/60	52/60
2 seconds	25/60	DONE	26/60	22/60
W.A.I.S.- R.**				
Similarities	10		12	
Arithmetic	7		8	
Digit Span	10		11	
Block Design	5		7	
Digit Symbol	7		6	
F.S.I.Q.***	89		94	
N.A.R.T.****	102			
Boston Naming Test	59/60		58/60	
Word Fluency *	(1)		(2)	
Category	14		12	
Easy letter	18		14	
Hard letter	6		7	
Repetition	80/100		85/100	
Token Test	20/21		20/21	

** Age Scale Scores
* Alternate Forms
*** Full Scale I.Q.
**** National Adult Reading Test

† NOTE: An explanation of the timing of the assessments in general is given on pages 54 & 55. The precise timing for each case is provided as part of the case description.

son who reported mild to moderate problems in this area.

Psychosocial Factors

On the Hospital Anxiety and Depression Scale, R. reported borderline depression and a very severe degree of anxiety (Table 7.66). Her son's reports on both mood ratings were virtually asymptomatic. R.'s subjective burden was moderately severe prior to treatment (Table 7.67). Her son's self-rating fell well below this, in the low range. Both R. and her son report numerous problems on initial interview, and there was high agreement as to the nature of these, showing a range of physical, cognitive and emotional/behavioural changes (Table 7.68).

Treatment

Because of the urgent nature of R.'s temper outbursts, which occurred approximately three times a week and involved physical violence, this was tackled first, although it was felt that her cognitive problems were contributing to the stress triggering off outbursts*. Memory failures recorded on checklists by the patient (after treatment for temper had begun) rose over the baseline period, eventually settling between 45 to 60 failures per week (Table 7.69). by her third week of treatment she was having no outbursts and memory techniques were introduced. By this time she had become more relaxed, although was still easily rattled and lacking in confidence. Her concerns about her self-value had shifted away from her role as a mother and wife to her cognitive functioning and she frequently described herself as 'stupid' and 'daft' when discussing her memory problems. In view of this, it was considered best to keep techniques

*R.'s temper data can be seen in the Appendix.

Case # 9 (R.V.)

Day to Day Memory Questionnaires

Table 7.64:Everyday Memory Questionnaire*

Assessment #	1	2	3	4
Patient	79(62)	-	21(16)	20(16)
Relative	19(15)		11(9)	- «
Agreement **	9/15 (60%)		7/14 (50%)	

Table 7.65:Cognitive Failures Questionnaire*

Assessment #	1	2	3	4
Patient	84(84)		21(21)	21(21)
Relative	15(47)		7(22)	- «

Psychosocial Data

Table 7.66:Hospital Anxiety and Depression Scale

Assessment #		1	2	3	4
Anxiety	- Patient	20	-	6	5
	- Relative	5	-	2	1
Depression	- Patient	10	-	1	1
	- Relative	1	-	1	1

Table 7.67:Subjective Burden

Assessment #	1	2	3	4
Patient	7	-	0	0
Relative	3	-	0	0

*Figures in parentheses are percentages of total possible score, as questionnaires differ in total number of items.
**% agreement by patient and relative on items endorsed.
« Relative had left home and felt unable to comment.

Case # 9 (R.V.)

Table 7.68: Problems Reported on Interview

	Pre-treatment		Post-treatment	
	Patient	Relative	Patient	Relative
Balance	+		Not Available	
Dizzy	+	+		
Headaches	+	+	+	
Tiredness	+	+	+	
Sleep	+	+		
Slowness		+	+	
Tension/Anxiety	+	+	+	
Impatience	+	+	+	
Noise Distressing	+	+	+	
Irritability	+	+	+	
Temper	+	+		
Violence	+	+		
Wordfinding	+	+		
Understanding	+			
Concentration	+	+		
Memory	+	+	+	
Depression	+	+		
Childishness	+	+		
Moodiness	+	+	+	
Personality Change	+	+	+	
'Not bothered'	+		+	
Disabled/Dependent			+	
Job Prospects	+	+	+	
Leisure Social	+	+	+	
Sex Life	+	+	+	
Total	23	21	15	
Agreement*:	Pre- 83%		Post- 24%	

*Percentage of agreement between patient and relative on problems endorsed on interview questionnaire.

simple in order to minimize stress and maximize her sense of competence. The techniques introduced included the Daily Activity Schedule, the Daily Diary and Pinboard.

As she was already very much accustomed to keeping a diary and record from her temper treatment, the techniques were introduced to R. all at one time and she was encouraged to pace herself and gradually normalize their use by incorporating them into her domestic routine. Her son backed up her efforts, although he reported an initial hesitancy in prompting or correcting her for fear of triggering an outburst. As shown in Table 7.69, she experienced an immediate drop in the total number of memory failures per week, from 56 to 39 failures per week and she continued to benefit without relapse. It appeared that gains were primarily made through her use of the DAS which she found therapeutic in that it helped her realize how much she could actually remember with a little prompt, whereas before she had become so rattled when trying to draw on her own memory that information seemed to become less accessible the more she tried. Her children shared the Pinboard with her and she began to see herself as a full member of the family, rather than invalid.

During treatment her husband returned to live with her and attended a session for an exchange of information. He described his wife as having become much more like her pre-morbid self but with rather more seriousness and modesty, listening more to what others had to say. He felt that her memory had improved as had her personality and that her subjective memory failures seemed to relate to her confidence. That is, when she was unsure of herself she tended to forget more and depend more on others. Having her own system of reminding, however, resulted in her confidence returning more quickly.

CASE # 9 (R.V.)

TABLE 7.69:Total number of reported memory failures per week during baseline and training phases as recorded on Memory Checklists.

	Week #	1	2	3	4	5	6	7	8	9	10	11	12	13
Baseline (P)		33	38	48	49	58	56							
Treatment (P)		39	20	12	7	6	2	2	2	0	0	0	0	0
Follow Up (P)		0	0											

By the end of treatment, R. was not recording any memory failures and she seemed to be remembering most things well. She felt confident in herself and felt that she had become a better person through her training. She was no longer experiencing any temper outbursts and her son confirmed that she was easy to live with. She had obtained a part-time job as a waitress in a busy restaurant and appeared to be coping well with this new role. Her son was planning to leave home to join the Navy but with her husband having returned, she did not anticipate feeling abandoned.

Post-Treatment

At the end of treatment, R. had reported no memory failures at all for five consecutive weeks. This success was reflected in the scores on day to day memory questionnaires. On the Everyday Memory Questionnaires, R. reported memory failures occurring less than a third as often as her initial assessment and this was maintained at follow-up (Table 7.64). Her son's score (only available at the end of treatment, as having by now left home, felt unqualified to comment on day to day measures) also indicated a reduction in everyday memory. On the Cognitive Failure Questionnaire (Table 7.65), R. also reported a marked reduction in her experience of absent-mindedness and maintained at follow-up. Her son's score at the end of treatment also fell significantly. Neuropsychological assessment after treatment did not indicate that any further recovery had taken place since her initial assessment (Table 7.63).

Psychosocial measures also reflected marked improvement in this patient. Her scores on the Hospital Anxiety and Depression Scale fell from their previous significant levels to below borderline, and this was maintained at follow-up. Her son's scores remained negligible (Table 7.66). Neither

R. nor her son reported experiencing any subjective burden at either post-treatment assessment (Table 7.67). On the Interview Questionnaire, she reported few problems than she had initially, with particular improvement in her behaviour and mood (Table 7.68). Her husband attended her follow-up assessment and described her as 'better than ever' in terms of emotional stability and conscientiousness.

Case # 10 (H.D.)

Demographic and Family Setting

H. was a 29 year-old man who sustained a very severe head injury in a road traffic accident. He had previously worked as a production officer on an oil rig but was laid off because of the effects of his injury. His demographic details are shown in Table 7.2. Prior to the injury he and his wife had been intending to divorce and he had been living with his parents while she continued to look after their two small children. After the injury however, his wife wished to look after him during his convalescence and he returned to their marital home. This had originally been intended to be a temporary arrangement after which they would proceed with the divorce.

Neuropsychological Profile

Table 7.70 shows the results of H.'s pre-treatment assessment. This showed that he was experiencing significant problems in memory and new learning as well as difficulty in concentration and mental tracking. He also demonstrated higher level word finding problems, particularly evident in discourse. Reasoning ability appeared to be intact, i.e. high average. Because of frequent and severe temper problems, the baseline record was cut short and treatment begun without a second pre-treatment assessment.

Day to day Memory Prior to treatment, both H. and his wife reported frequent forgetting and cognitive failures, persisting through the baseline phase (Tables 7.71 and 7.72). There was complete agreement between them as to the types of errors made on the Everyday Memory Questionnaire,

Case # 10 (H.D)

Table 7.70: Neuropsychological Data for Case # 10

	Assessment #†			
	1	2	3	4
Logical Memory*				
Immediate	5	NOT	11	11
Delayed	5	DONE	11	6
Paired Associates*				
Easy	8		8	8
Hard	4		1	5
Total	12		9	13
Rey-Osterreith*				
Copy	29		35	32
Immediate Recall	14		24	17
P.A.S.A.T.				
4 seconds	51		53	52
2 seconds	25		26	22
W.A.I.S.- R.**				
Similarities	10		12	
Arithmetic	7		8	
Digit Span	10		11	
Block Design	5		7	
Digit Symbol	7		6	
N.A.R.T.***	102			
Boston Naming Test	59		58	
Word Fluency*				
Category	14		12	
Easy letter	18		14	
Hard letter	6		7	
Repetition	80/100		85/100	
Token Test	21/21		21/21	

** Age Scale Scores
* Alternate Forms used
*** National Adult Reading Test

† NOTE: An explanation of the timing of the assessments in general is given on pages 54 & 55. The precise timing for each case is provided as part of the case description.

although Mrs D. reported a higher frequency of failure than H. seemed aware. Their reports on the Cognitive Failures Questionnaire closely parallelled those on the EMQ.

Psychosocial Factors

Severe stress was also indicated by the couple's Hospital Anxiety and Depression scores (Table 7.73) which showed that both partners were experiencing high levels of anxiety and depression, although H.'s scores were slightly lower than those of his wife. These lessened very slightly over the baseline period but remained significant. Subjective Burden scores were very high for both partners throughout the baseline period (Table 7.74). The couple largely agreed on the nature and number of changes that had occurred in H. since his injury, which ranged across all areas of functioning. Although H. was aware that his employment prospects had been negatively affected, he was not upset by this as he had not enjoyed his job on the rigs. Both agreed that his personality had changed (Table 7.75). His wife described him as having been rather impatient, dependent and self-centred person who ignored his domestic responsibilities when at home, preferring to spend his time drinking and driving around with friends. Since his injury, these pre-morbid characteristics were much enhanced. According to his wife, they had had severe problems in their marriage for over a year before his injury. Although she now found him even more difficult to deal with she excused it as being due to his head injury and was no longer actively proceeding with the divorce. As regards rehabilitation she felt she would 'give it a go' to see if he improved enough to be compatible. H. himself attributed all of his current problems to his injury and said he had not wanted to divorce and now hoped they would stay together.

Case # 10 (H.D)

Day to Day Memory Questionnaires

Table 7.71:Everyday Memory Questionnaire*

Assessment #	1	2	3	4
Patient	87(68)	93(73)	47(38)	44(34)
Relative	10(86)	112(88)		
Agreement **	100%	100%		

Table 7.72:Cognitive Failures Questionnaire*

Assessment #	1	2	3	4
Patient	65(65)	71(71)	32(32)	24(24)
Relative	28(88)	27(84)		

Psychosocial Data

Table 7.73:Hospital Anxiety and Depression Scale

Assessment #		1	2	3	4
Anxiety	- Patient	16	14	8	8
	- Relative	16	13	9	
Depression	- Patient	12	10	10	11
	- Relative	13	12	8	

Table 7.74:Subjective Burden

Assessment #	1	2	3	4
Patient	9	9	8	8
Relative	10	10	9	

*Figures in parentheses are percentages of total possible score, as questionnaires differ in total number of items.
**% agreement by patient and relative on items endorsed.

Case # 10 (H.D)

Problems Reported on Interview

	Pre-treatment		Post-treatment	
	Patient	Relative	Patient	Relative
Vision	+	+		
Hearing	+	+	+	+
Dizzy	+			
Headaches	+	+	+	+
Tiredness	+	+	+	
Sleep	+	+	+	+
Tension/Anxiety	+	+	+	+
Impatience	+	+	+	+
Noise distressing	+	+	+	+
Irritability	+	+	+	+
Temper	+	+	+	+
Violence	+	+	+	+
Speaking	+		+	
Wordfinding	+	+	+	+
Concentration	+	+	+	+
Memory	+	+	+	+
Depression	+	+		+
Childishness		+		+
Moodiness	+	+	+	+
Personality Change	+	+	+	+
'Not bothered'	+	+	+	+
Supervision		+		
Job Prospects	+	+	+	+
Leisure/Social	+	+	+	+
Sex life		+		
Total	22	23	19	19
Agreement*:	**Pre-** 80%		**Post-** 81%	

*Percentage of agreement between patient and relative on problems endorsed on interview questionnaire.

Treatment

Because of the severity and frequency of H.'s temper outbursts (see Appendix), this problem was tackled first but because there seemed a clear relationship between memory failures and temper outbursts, memory strategies were introduced soon after treatment began. Memory checklists kept during the eight week baseline period (recorded by H. only) indicated frequent memory failures ranging between 63 and 83 per week (Table 7.76).

Memory techniques introduced included the Daily Activity Schedule, Daily Diary and Pinboard.

H. was dismissive of the form of the DAS as it looked 'like it's for handicapped people'. While he was still encouraged to try it he was not pressed and a more conventional diary was adapted to incorporate this and the Daily Diary. For a similar reason he balked at the Pinboard but his wife accepted the handouts for the techniques and commented that although H. needed the techniques, he could not admit this, often losing his temper when forgetting things. (H. had shown a similar attitude to the temper handouts initially. On one occasion his wife discovered during a session that he had removed the record forms that she had put in her handbag before leaving for the appointment). By his third session he was using these methods very regularly, indeed appearing over reliant on them, checking them every 20 minutes and often unnecessarily referring to them when talking. His dependence was also manifested in his relationship with his wife. She was beginning to find that, although she felt valuable helping him, he had become 'even more of a child' than he had been before the accident and constantly demanded her attention. In the middle of the treatment phase she asked him to leave and he returned to his parents. They

CASE # 10 (H.D.)

Table 7.76:Total number of reported memory failures per week during baseline and training phases as recorded on Memory Checklists

Week #	1	2	3	4	5	6	7	8
Baseline (Pt)	63	75	78	83	76	77	71	80
Treatment (Pt)	41	30	15	12	16	10	11	8
Follow-up (Pt)	8	11						

continued daily contact so he could see their children and she agreed to continue in her role as co-therapist. However, she rarely attended later sessions yet H. coped with his mnemonic strategies on his own without difficulty. He felt he was obliged to as his parents insisted that he was 'just the same' as before the injury. Despite this, they felt his wife had been callous at leaving him so soon after his injury.

These issues of dependence and personality enhancement were the basis of the final treatment sessions. It appeared that denial had been a characteristic of his before his injury and this had not only become part of his post-injury personality but was being reinforced by his parents. At his final session H. had begun working voluntarily with handicapped children which he felt helped him to be less self-centred and more aware of his own level of competence. His wife attended the final session and confirmed that he had made considerable gains in regard to memory, using the strategies as a matter of habit. She was disillusioned, however, by his return to pre-morbid activities and his selfish behaviour. He was having an affair and she expressed bitterness at his apparent lack of appreciation for her caring role. She had resumed divorce proceedings, feeling she had given him a chance which he had not used. He himself felt depressed by the finality of her departure and was beginning to feel that it was not worthwhile making any further effort at rehabilitation.

Post-Treatment

At the end of treatment H. had maintained the improvement in his day to day memory that he had begun to show after the first few weeks of treatment, making only a few failures per week (Table 7.76). This improvement was reflected in his

scores on day to day memory questionnaires. His EMQ score at the end of treatment was nearly half of that prior to treatment and this was maintained at two months follow-up (Table 7.71). His score on the Cognitive Failures Questionnaire closely mirrored these at both assessments (Table 7.72). His wife's reports are unavailable as she felt unable to comment in view of her withdrawal from his day to day life. Neuropsychological assessments following treatment slowed no significant recovery in cognitive functioning (Table 7.70).

The improvement in day to day memory was not reflected by psychosocial measures. H.'s anxiety scores did show a marked reduction from pre-treatment levels, now falling below the borderline range on both post-treatment assessments. His depression levels remained largely constant over all four assessments (Table 7.73). His wife's anxiety also appeared to fall by the end of treatment, falling in the borderline range and her depression score also showed a modest reduction. However, follow-up data is unavailable for her and it cannot be assumed that these held steady. Subjective Burden scores remained high for both H. and his wife (Table 7.74), not surprisingly in view of the ongoing deterioration in their relationship. The numerous problems reported on initial interview largely remained at follow-up (Table 7.75), according to both H. and his estranged wife and they continued to agree on the nature of these.

CHAPTER VIII

Discussion

DISCUSSION

The main dependent measure used in this study was a record of the frequency of memory failures. The record was made at the time of the failure, by the patient and/or relative. Figure 8.1 allows an overview of treatment effectiveness for all ten cases.

The Baseline Phase

Case 2, 3, 4, and 7 clearly show stable baselines recorded, where there was minimal variability in frequency during the baseline phase. Cases 1 and 6 demonstrate a reduction in frequency from the onset of baseline recording, steadying after the first week(s) to four consecutive weeks of stability. In these two cases, few failures were recorded from the outset, but the act of keeping a record itself appeared to have a mild mnemonic effect by making patients more aware of failures. Both of these patients reported their day to day memory had improved by the end of the baseline phase, although this was not supported by EMQ's nor did neuropsychological evidence indicate any spontaneous recovery. The remainder of the cases (5, 8, 9 and 10) showed rising baselines and apart from case 10, this increase is quite marked and sudden. This again suggests that recording memory failures increased awareness and resulted in a more accurate reflection of the patient's memory failures as suggested by their neuropsychological status. For 2 and 5, however, it also seemed to make relatives more aware of failures previously masked by a) environmental factors and b) bluffing. In all of these cases the baseline records settled to a narrower range, suggesting insight was gained fairly immediately and maintained thereafter and was not a gradual and continuous process.

MEMORY FAILURES

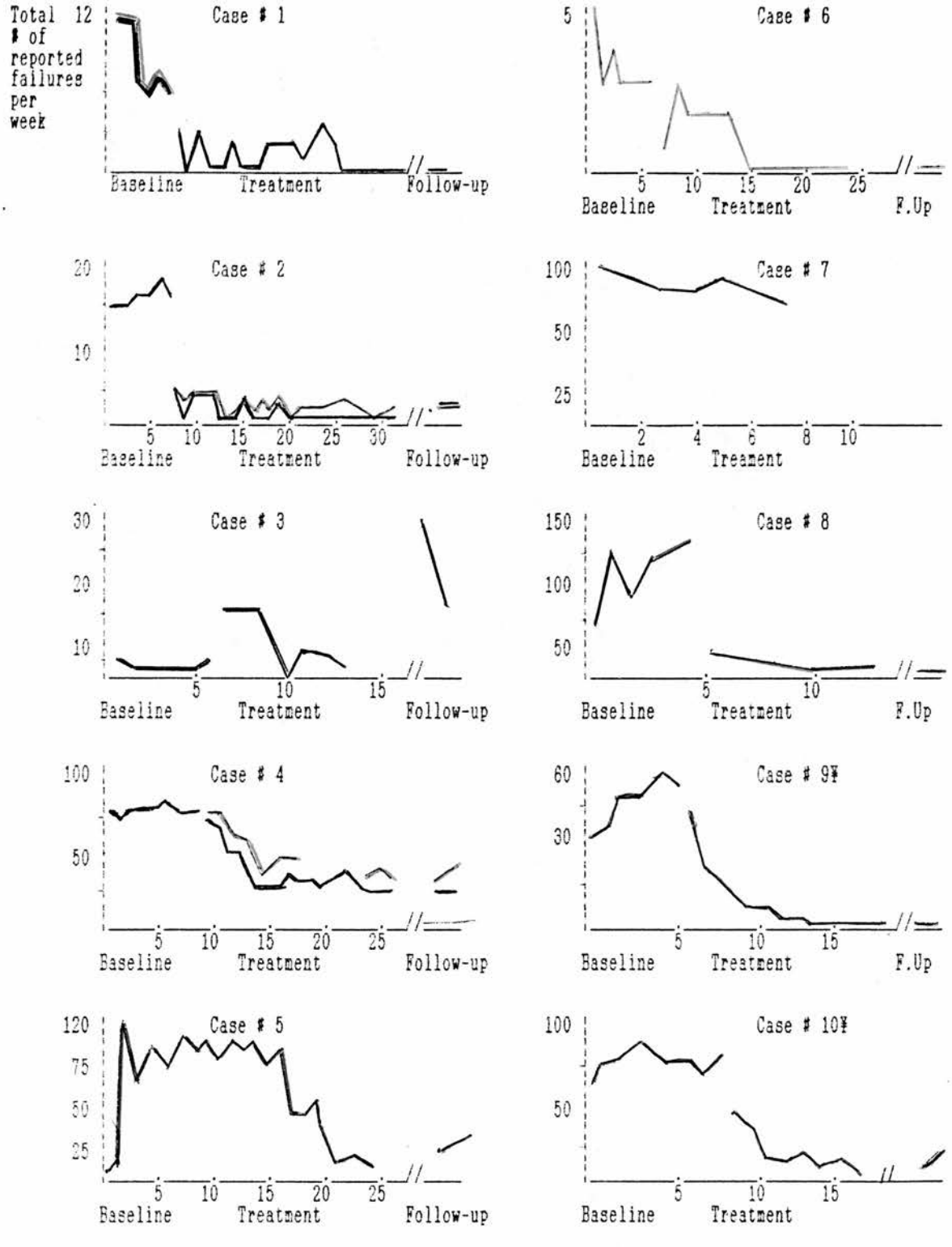


Fig 8.1 Total Number of Reported Memory Failures per week, as Recorded on Memory Checklists.
* Recorded jointly
¥ Recorded by patient only.

The overall stability of the baseline suggests that the Memory Checklist is a relatively efficient and unstressful means of recording memory failures following severe head injury. For the majority of patients and relatives the brevity of the list made this task manageable and yet allowed room for more idiosyncratic failures to be added. It also helped patients and relatives get into the habit of observing and recording which eased the introduction of strategies which they would have the responsibility of keeping up to date, and helped them become aware of the specific problems to be targeted.

Effectiveness of the Memory Strategies.

In a multiple-baseline design, treatment effectiveness can best be measured by considering the following: 1) how many cases had stable baseline and 2) showed results at the end of treatment below the baseline range. The stability of the baselines has already been discussed. Deciding whether results fall below the baseline range is less problematic and can be described as when the last 2 or 3 points, or the last quarter of treatment scores are below and not overlapping with the baseline range.

Following this definition, cases 1, 2, 4, 5, 6, 8, 9 and 10 can be considered clearly successful. Cases 3 and 7 are clearly failures.

The successful cases will be considered first. Those showing stable baselines (cases 2 and 4) demonstrated two different patterns of treatment effect. In case 2, the onset of treatment showed a sudden drop in the already moderate frequency of memory failures and improvement continued steadily. No increase was shown despite the patient's increasing independence. In case 4, who recorded

a very high frequency of memory failures prior to treatment, there was no clear evidence of treatment effectiveness until week three, and only by the fifth week of treatment did he really demonstrate consolidation of mnemonic effectiveness. In view of his gross memory problems, in the absence of prompting from his wife throughout treatment, this patient's benefit from the strategies appears remarkable. His success can be attributed to his good insight, his assiduous use of each technique as it was introduced and his surprising ability not to become discouraged or overwhelmed despite his situation. Those cases showing dropping baselines, where the act of recording itself seemed to serve as a memory aid (cases 1 and 6), both were recording few memory failures per week. Both also led fairly sheltered lives and were rather avoidant. In such conditions, it is not surprising that a Memory Checklist might have a mnemonic effect where there is so little to forget. Both showed a marked, immediate drop with the introduction of the strategies, followed by some variability of the first weeks of treatment. Their memory failures were few, however, and finally diminished to none at all. While it might have been expected that the frequency of forgetting would increase as they became more independent, it needs to be considered that 'independence' still involved a highly structured day centre or family setting and memory was not being tested in the kind of situations the patients would have been exposed to prior to their injuries.

Cases where the baseline had risen provide particularly interesting clues to the effect that keeping a day to day record has on the patient's (and relative's) insight. In cases 5, 8, 9 and 10 all had played down memory problems at initial interview, either because of frank denial, or as in cases 8 and 9, because temper outbursts had predominated. Case 5 had shown in many ways her lack of acceptance of her

profound memory problems. Her striking veneer of coping contrasted sharply with her neuropsychological test results and her degree of amnesia when asked to recall very recent events. Her parents clearly had believed her memory was not as poor as it actually was and the baseline recording and introduction of memory strategies enabled them to see more accurately the difficulties their daughter encountered, and her resistance to facing these directly. That cases 8, 9 and 10 all presented with temper problems initially and showed rising baselines raises further questions about denial and insight. In all three cases, quite urgent treatment for temper was justified by the severity of their temper outbursts, and it is not suggested that memory should have been tackled first. However, temper outbursts themselves were very often the effect of the patient's unwillingness to face problems related to the effects of the head injury and usually involved a lack of insight into the degree to which their behaviour was a problem. In case 10, unwillingness to admit vulnerability had been a pre-existing characteristic which had become enhanced following his injury. However, in cases 8 and 9, it seemed that while denial was present, these two were very ready to acknowledge memory failures soon after baseline records had begun, and it therefore seems that the initial low recording was genuine lack of awareness due to preoccupation with temper problems. Both showed a high degree of emotionality and suggestibility during treatment, and there may have been a degree of psychological overlay in their improvement. It is worth nothing that their temper records showed similarly dramatic results.

The two cases where treatment clearly failed merit careful consideration. Case 3 was unable to keep an independent record of memory failures, but even though his parent's seemed aware that his memory was very poor, they recorded a

low frequency, apparently due to their constant supervision. At the onset of treatment, the frequency nearly trebled, although there had been no change in lifestyle to account for this. It appeared that the introduction of the Daily Activity Schedule not only increased his parents awareness of how much he was forgetting, but because of the increased responsibility it put on him, the more opportunity it raised for forgetting. After a few weeks, his parents were doing everything apart from filling it out for him, resulting in an apparent reduction in his memory failures. Treatment ended as they had planned a trip abroad, but there is nothing to suggest that further treatment would have led to any improvement, and at follow-up it was clear that their increased awareness led them to observe more episodes of forgetting than ever before. From a clinical perspective, JM appeared an extreme case. He showed marked frontal features, including disinhibition, lack of insight and impulsive, fatuous behaviour. His parents were certainly cooperative and supportive of treatment aims, and motivated to try and change his behaviour. His lack of improvement, despite family support supports the view that patients with marked frontal features do not, in the main, benefit from rehabilitation (e.g. Prigatano, 1986). Case 7 also appeared to be an extreme case, but in markedly different ways from Case 3. he was a very intelligent University student with high aspirations prior to his injury. Unlike Case 3, he had good insight into the degree of his deficits, which distressed him a great deal. Yet he held unrealistic expectations of treatment from the beginning and expressed a fantasy of 'waking up someday with my memory back'. These factors, in addition to his angry resistance to paper and pencil memory aids, suggest that he was experiencing psychological denial and was unable to come to terms with the effects of his head injury. In addition, he had to deal daily with the spectre of his father's demented

state and fears of becoming like this may well have underlay his denial. Such a case would suggest that psychotherapy rather than memory rehabilitation would be the most appropriate first step for patients like him.

Relationship to Neuropsychological Status

In the main, neuropsychological recovery did not appear to be a relevant factor in patients' response to treatment methods. While a few patients showed slight improvement in some areas at follow-up, compared to their initial assessments, only one patient (Case 6) showed significant improvement in new learning. While this is likely to have played a role in his ability to benefit from the memory strategies, there were other cases who showed similar treatment response, without corresponding improvement in neuropsychological status (Cases 1, 2, 4, 9 and 10). Even the presence of marked global deficits did not prove to be a barrier to treatment. (For example, Case 2). Instead, it appeared that psychological and behavioural characteristics placed greater obstacles to patients' ability to benefit, as shown by the two cases which failed.

Appropriateness of Techniques

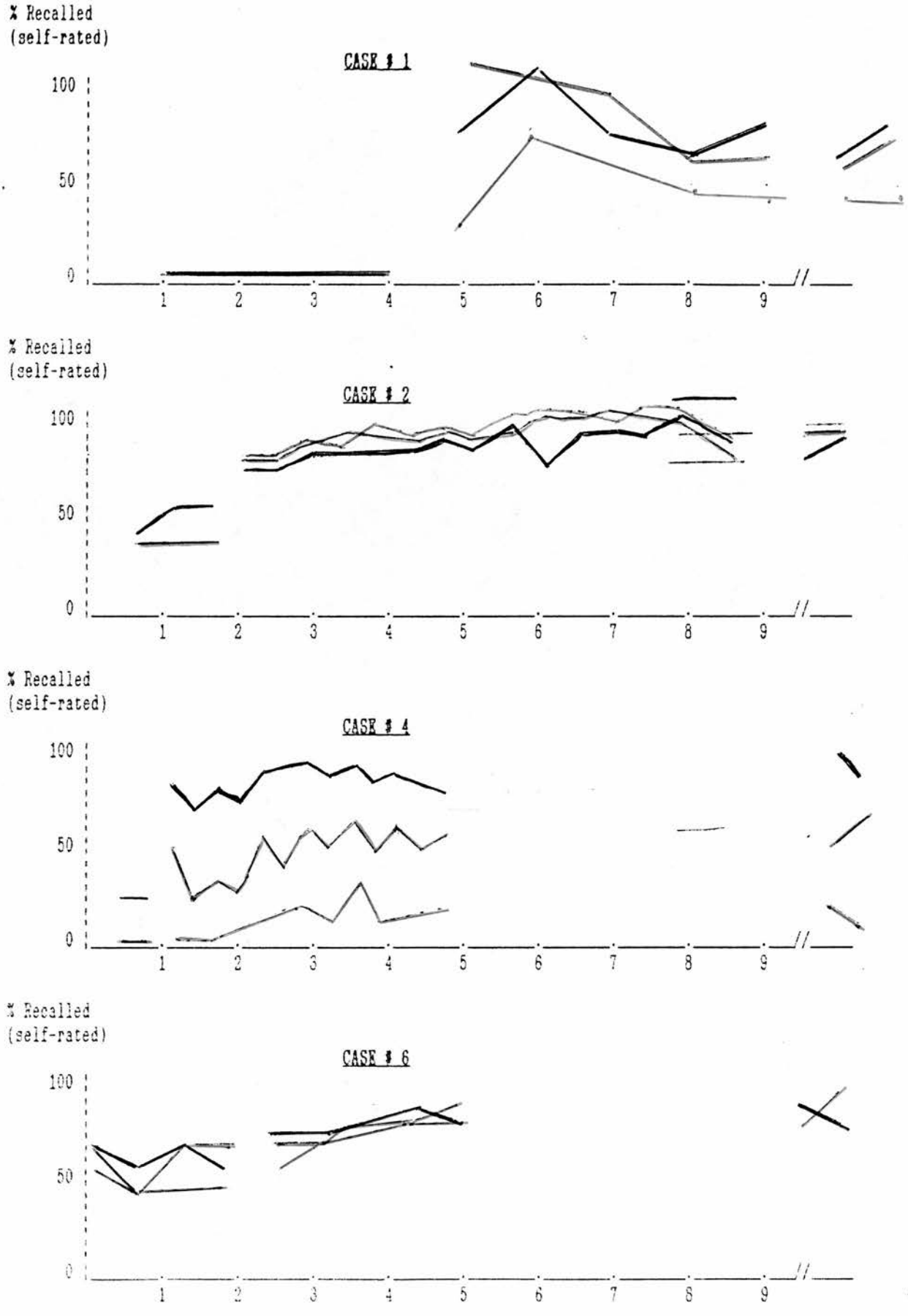
The majority of patients showed clear success in their application of the memory strategies, and their effectiveness has been demonstrated. The usefulness of the Memory Checklist as a means of recording day to day memory failures has already been mentioned. The other methods were also found acceptable to most patients and the structured, step-wise approach in which they were introduced enabled them to be learned by both patients and relatives and thus amenable to generalisation in other settings.

The techniques appeared to have good face value, and although may have initially seemed rather obvious or simplistic, they evolved as a realistic means of reducing the frequency of memory failures in memory impaired individuals. However, for those patients having difficulty with, or failing to come to terms with their problems (Cases 5, 7 and 10), their simplicity was unacceptable and alternative solutions had to be found. Generally, however, the methods proved to be adaptable to individual's settings or personal needs.

The main problem with the methods, particularly initially, was whether or not the patient could 'remember to remember', as inevitably, even a checklist is a memory task itself (Sunderland et al, 1983). A further problem was that most patients were still forgetting things, even when their use of all the methods were running smoothly. There are a number of memory failures that are not 'caught' by these methods, particularly events falling prior to the most recent Daily Activity Schedule (although case 2 reported that he sometimes sat down and perused past DAS's for enjoyment), and on the spot failures such as names, faces and places. Memory rehabilitation methods for these specific problems have been described in the literature and found to be successful (e.g. Wilson, 1987). In this study, however, to prevent treatment methods from becoming unwieldy, compensatory social skills were usually suggested to overcome awkward moments. Finally, the methods involve hard work, most often in the initial stages. PQRST (Figure 8.2) in particular demanded consistency and continuity, and much prompting by relatives. Once the method became more familiar, however, patients showed more initiative in practising it, although it still seemed important that they schedule it on their Daily Activity Schedule to avoid PQRST sessions becoming superseded by more enjoyable and less

Figure 8.2

P.Q.R.S.T.



— = Recall after ½ hour

— = Recall after 1 hour

— = Recall after 24 hours

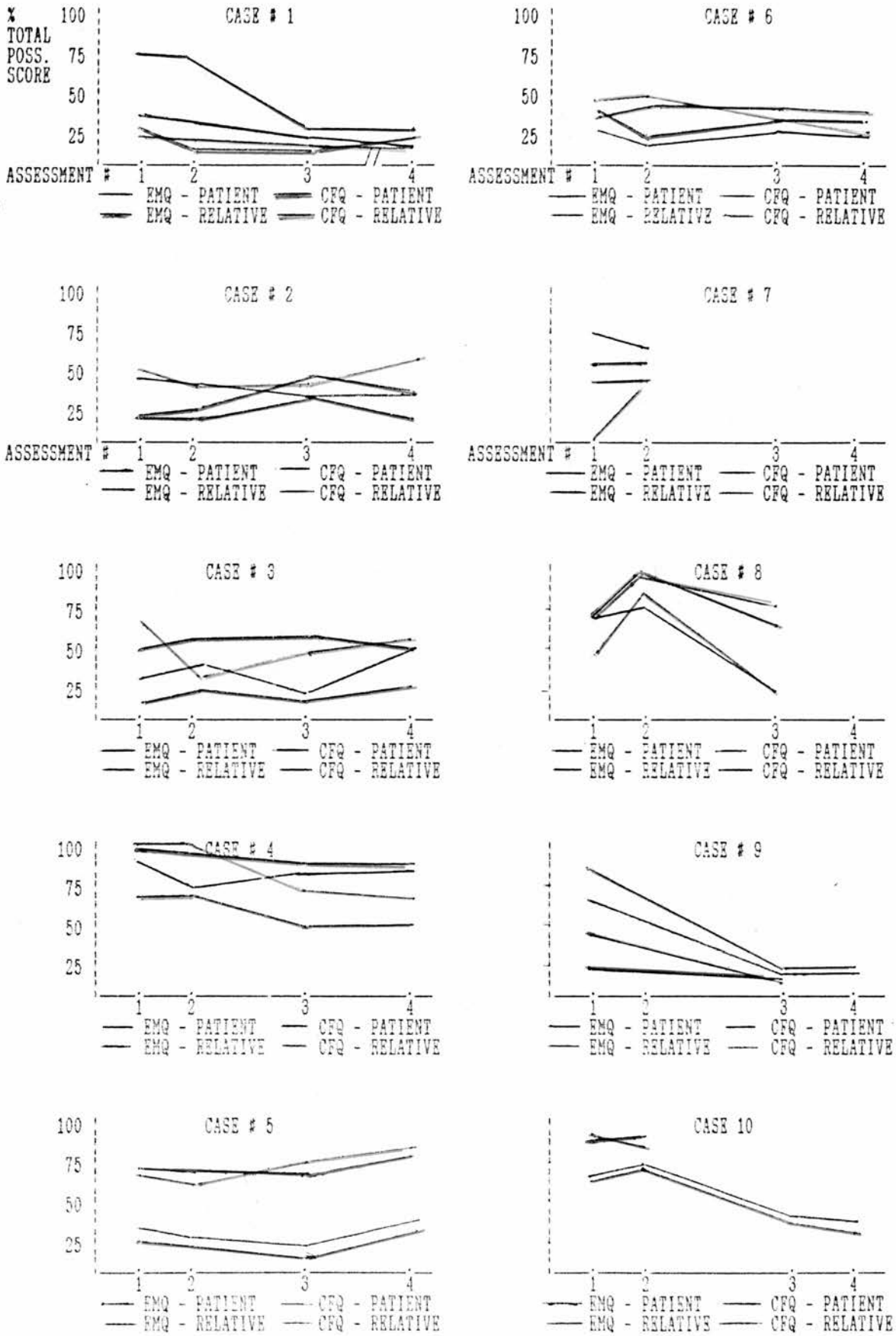
taxing activities.

Everyday Memory Questionnaires

Table 8.3 depicts the changes in scores on the Everyday Memory questionnaire and Cognitive Failures Questionnaire. There was no overall trend for these questionnaires to reflect the improvement recorded on Daily Checklists. A few patients showed marked reductions on the EMQ by follow-up (Cases 8, 9 and 10) but only in one of these (Case 9) did the relative agree on this. Improvement as indicated by lowered CFQ scores was more widespread, but agreement between patient and relative was rare. The persisting moderate to severe frequency of memory and cognitive failures reported on these measures supports the observation stated above that, despite improvement in day to day memory failures noted by patients and relatives, many failures continue to occur and are not picked up by the methods used. This is not surprising when the items included on these questionnaires are considered. On the EMQ, a number of items include misplacing items, forgetting names, or becoming muddled in conversation, while on the CFQ, items tend to focus on absent-minded mistakes and tip of the tongue phenomena. In the present study, it would not have been feasible to attempt to incorporate further techniques to accommodate these errors which may be best tackled by more sophisticated cognitive remediation methods, such as verbal regulation or self-instructional techniques (e.g. Yvlisaker, et al, 1987). Other items, such as difficulty concentrating while reading, although improved by the memory strategies, do clearly still persist and the methods are by no means a panacea.

Figure 8.3

MEMORY (EVERYDAY)



Psychosocial Factors

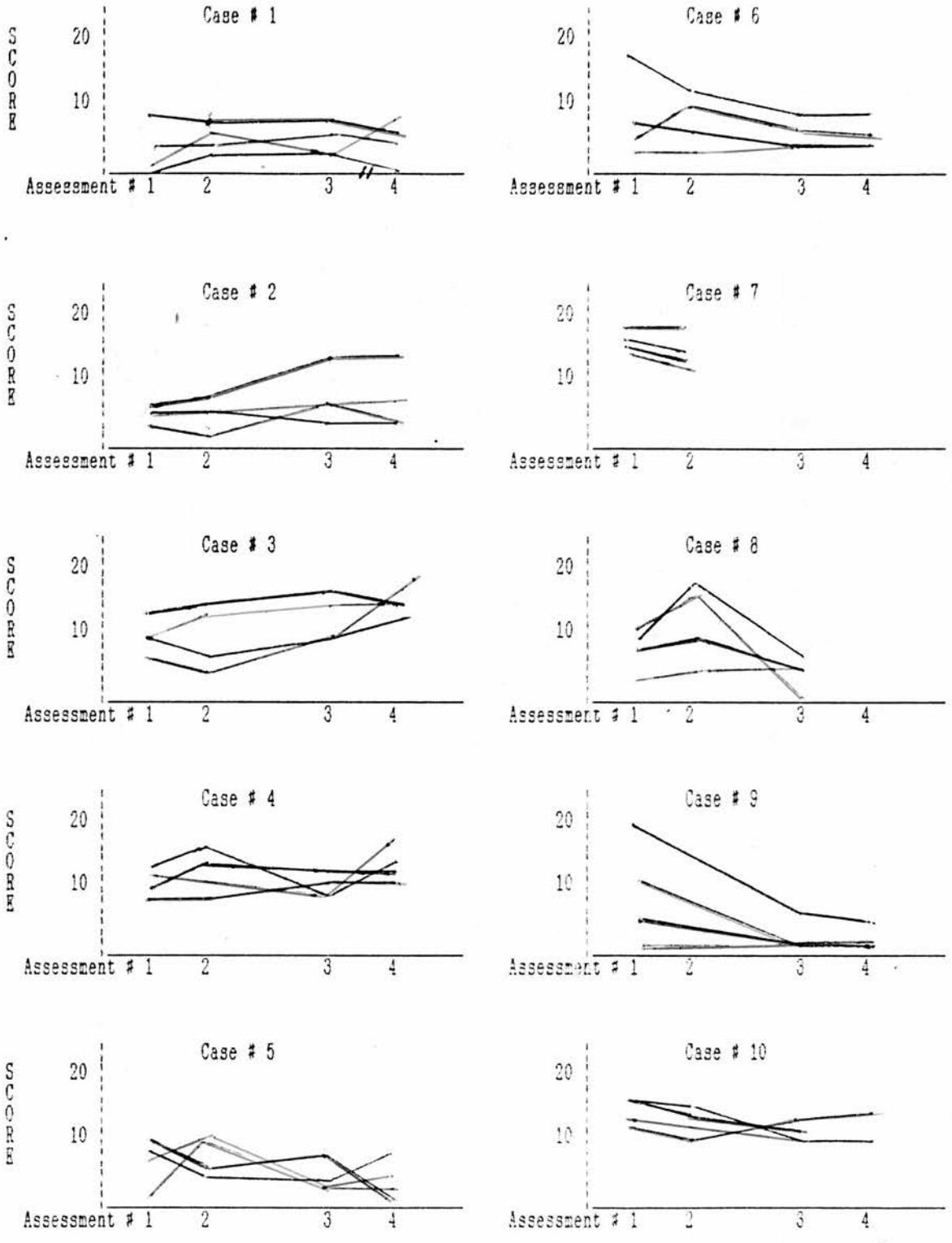
Figure 8.4 shows the levels of depression and anxiety reported by patients and relatives over the four assessments. Taken together, they do not suggest that improvement on day to day memory necessarily led to any subjective improvement in mood as measured on the Hospital Anxiety and Depression Scale. There was a tendency for patients to report higher levels of anxiety than relatives throughout the programme. No frank difference in depression levels between relatives were demonstrated overall. In individual cases, however, there were some striking cases of congruency in mood assessment patterns between patients and relatives. At initial assessment, six of the ten patients were experiencing levels of anxiety which fell between borderline to clinical levels of anxiety (Cases 3, 4, 6, 8, 9, and 10). In only three of these (6, 9, and 10) had anxiety visibly diminished by follow-up and in each of these the pattern was closely followed by relatives' reports, albeit at lesser degrees. No patient showed a marked increase in anxiety when initial and follow-up scores are compared, but a few (1, 4 & 8) showed an increase in anxiety at the onset of treatment.

Patients were less likely to suffer from significant levels of depression than from anxiety and only three patients reported borderline to clinical degrees of depression at initial assessment (4, 7 and 10). However, there was a clear trend for depression levels to increase by the beginning of treatment (1, 5, 6, and 8) or by the end of treatment (2, 3 and 4).

Relatives were just as likely as patients were to show significant levels of anxiety at initial assessment. Overall, six relatives reported anxiety levels at borderline level or above initial assessment (3, 4, 5, 7, 9 and 10) and

Figure 8.4

H.A.D. SCALE



in three of these it fell in the clinical range. By follow-up only cases 5 and 8 had fallen below borderline levels.

As regards depression experienced by relatives, cases 3, 4, 7 and 10 showed borderline to clinical levels at initial assessment and in the two cases for which follow-up data is available, this had in fact risen by the follow-up assessment, despite a decrease in 4 over the treatment period.

Given the small number of patients and the wide variation between them as to their reports of mood changes, this issue needs to be viewed cautiously. It does seem clear that changes and improvements in mood are evident in individual cases, but there is no indication of a general trend for anxiety or depression to be alleviated. In fact it appears sometimes to worsen, at least temporarily. It can be said that in some cases there is a tendency for patients' depression to rise between the onset and end of treatment, and this was certainly reflected in the comments made by almost all of the patients at some point during treatment. This expressed dysphoria most often appeared to be related to the increased insight they had gained as a result of recording memory failures and the confrontation with the degree to which memory problems persisted. At times it seemed to be related to the patient's realization that a 'dream' of recovery, for example, exactly one year after the injury, was not going to come true. This depression associated with increasing insight has been reported in the literature (e.g. Romano, 1974) and some authors have suggested that it is an essential step to the patient becoming able to accept and then tackle his/her problems (Lezak, 1981).

As regards the relative's view, it seems that for some, anxiety and depression levels remain high despite the

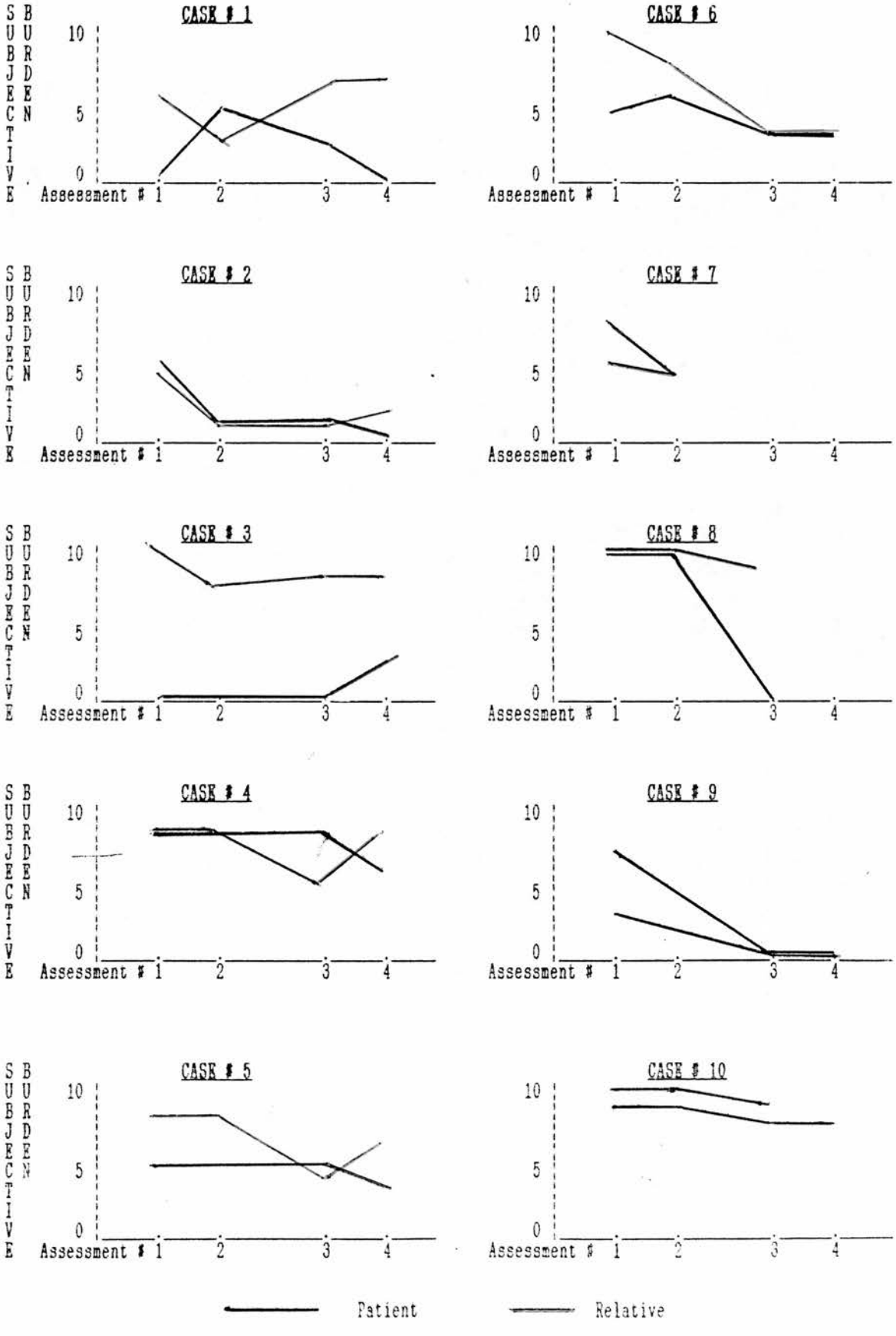
support provided within the treatment setting. It seems that treatment itself, while providing support to the relative, also raises new issues which provoke new anxieties, such as separation related to increased independence, insight into the patient's restricted capabilities and anxiety about the future when treatment ends. The offer of family based treatment itself may even be expected to raise anxiety in overstretched relatives, who may be searching for a treatment that will 'fix' the patient without their involvement (Ben-Yishay, 1982). The issue is clearly complex, however, and in many of the cases there was ongoing stresses unrelated to the patient's memory problems which would have also been contributory factors, such as family illness, or predisposing characteristics.

Subjective Burden

A simpler method of viewing change related to psychosocial stress is to look at the levels of burden reported by patients and relatives. Again, there were very individual patterns (Figure 8.5). Patients tended to report lower degrees of burden than their relatives. Only two patients reported experiencing no burden at all at initial assessment (1 and 3). Three patients reported moderate levels (2, 5 and 6) and the remainder reported high levels of burden (4, 7, 8 and 9). Only one case (1) reported a frank increase in the level of burden, occurring at the end of baseline, and this was paralleled by an increase in her depression score. This diminished over treatment and by follow-up had returned to nil. A reduction in burden was reported by 2, 8 and 9 by the end of treatment. Case 3 who did not benefit from treatment, reported no degree of burden at all until at follow-up when this was still mild. Interestingly, his report shows the greatest discrepancy found between a patient and relative. Case 7, who dropped out of

Figure 8.5

Psychosocial



treatment, showed a slight reduction in the burden reported, suggesting that he may have experienced some relief through his involvement with the programme, although his father's illness would be expected to contribute to his high score.

All relatives reported experiencing some degree of subjective burden related to the effects of the patient's head injuries. Three of these reported moderate levels of burden (1, 2 and 7), and six reported high levels of burden (3, 4, 5, 6, 8 and 10). Only one reported mild burden (Case 9), and in this case was the patient's child, who, despite the role reversal which occurred regarding memory failures, largely led a life independent from the patient whose problems had instead taken their toll on her marriage. In only one case, (1) had the degree of burden risen by follow-up, despite dropping at the onset of treatment (1). In this case, it seemed that, despite improvement regarding memory, the patient continued to deny many of the effects of her head injury and had begun to act out her difficulties through behaviour and at follow-up the discrepancy between her and her husband's report of burden was at its widest. Cases 2, 6 and 9 showed a marked reduction in the burden experienced and all of these patients had progressed to a higher level of independency by the end of treatment. In cases, 3, 4 and 5, the burden remained quite high. There is no common factor shared in these cases which might underlie this finding. Individual reasons for the persisting burden include, 1) lack of progress and persisting frontal features (3), 2) marital stress and continuing dependence, and 3) separation anxiety and feelings of protectiveness.

Contributing Factors

On the interview questionnaires completed by patients and relatives at the initial and follow-up assessments, there

were wide individual differences in the number of problems reported by patients and relatives and in the degree to which each pair agreed on the nature of the problems endorsed on the questionnaires. There was very little change in the degree to which patients and their relatives agreed regarding the nature of the problems endorsed, among those for whom follow-up data is available. Case 3 demonstrated closer agreement by the end of treatment and reported many more problems than he had initially, however, he had shown no benefit from treatment and still demonstrated a considerable lack of insight throughout. In case 5 there was a more marked merging of views by follow-up and this was also reflected in her increased insight over the baseline period and treatment. Her increased depression score would also support the idea that her awareness of the effects of her head injury had become more accurate over time, although she continued to report far fewer problems than her parents. The number of problems reported at follow-up was largely the same as at initial assessment, although in case 5, both patient and relative reported an increase in changes. It seems that, despite treatment a number of problems remain, ranging from the physical to the behavioural. Although some patients tended to focus on physical problems initially and to play down cognitive impairments, in general it was the latter that gave patients and relatives the greatest concern, concurring with other studies (McKinlay et al, 1981).

Overall, there seems no clear relationship between the numbers of problems reported nor degree of agreement and treatment outcome. Perhaps more importantly, there is no evidence that reporting of a high number of problems should be considered a barrier to treatment. Follow-up data are too incomplete to make any association between the relationship between the number of problems reported and degree of burden. However, this relationship has been noted

in other studies when emotional and behavioural problems prevail (e.g. Panting and Mary, 1972). They may well contribute to the subjective burden (McKinlay et al, 1981) and emotional states and therefore merit consideration when these are elevated. It can be concluded from this that memory remediation per se is not likely to reduce significant psychosocial problems and the severity of these suggest a more focused approach to these may be necessary. It therefore may be more appropriate in some cases to tackle the emotional problems, such as temper or depression, first.

Denial

Denial of the reality of the loss of cognitive and social skills was evident to some extent in virtually all of the cases and expressed directly or indirectly by either patient and/or relative. It was most obvious during the initial phase, by the patient´s reluctance to acknowledge memory problems, either through low recording of memory failures or resistance to treatment methods. Often initial compliance turned into sabotage when patients found themselves confronting and unable to mask the degree of their memory deficits. This is exemplified by case 5, who initially recorded very few failures, despite her visible confusion, but eventually acknowledged more. On introduction to the methods, she frequently lost her handouts, didn´t have a pen handy, or found some other reason why there were gaps in her records. As she gradually became more willing to admit her distaste for methods which threatened her well developed social persona, more acceptable methods, such as a Filofax, were adapted.

Denial was also expressed indirectly, in the fantasies and unrealistic expectations of some patients. Case 7, a bright university student who seemed ideally suited for mnemonic training, in view of his already creative and

practical use of strategies, became angry and dismissive when the methods were introduced. He repeatedly asked when he would get his memory back and when he finally dropped out of treatment, he 'shopped around' for computer based treatment and special education classes, which he also later abandoned.

Relatives also demonstrated denial, often by their expressed belief or wish for the patient to return to his/her premorbid status, despite obvious persisting cognitive and behavioural deficits. In case 4, lack of communication had prevailed in the marital relationship since the injury. It emerged during treatment that his wife was 'waiting for him to make the first move' towards a more affectionate and communicative relationship, despite of his striking lack of initiative and adynamia. As treatment began to bring about modest changes in her husband's behaviour, she began to experience anxiety and anger and threatened to abandon treatment.

In such cases, the force of denial is so great that rehabilitation efforts threaten the well-being of patients and/or relatives and thus also threaten the chance of compliance and cooperation to treatment goals continuing. This suggests that denial needs to be dealt with as it arises and before progressing with further memory remediation or social skills training. Memory remediation still may be the first problem to be tackled in such cases and indeed may provide the best vehicle to bring denial to the surface in the first place.

The Role of the Relative

As Co-therapists

In this study, relatives were found to be largely effective

as co-therapists. From the outset, most were very eager to know how to help the patient, in terms of physical and to some extent, recreational needs but did not know how best to help their day to day memory problems. The suggestion in other studies that families can play a valuable role in helping the head injured patient is well supported in the group studied here.

However, while relatives generally found it easy to learn memory strategies and back up their use, they found it harder to accept the increasing independence that this potentially provided for the patient. There was evidence in some cases that parents, in particular, felt ambivalent about 'letting go' and allowing the patient to experience new situations or make mistakes. Sometimes this was related to guilt regarding the original injury (Case 2, for example whose mother felt responsible for the original injury by having been too lax, and other times it seemed to related to separation anxieties following the very natural period of protectiveness felt towards the patient during the months following the injury. As children tended to be in their late teens or early twenties, parents tended to slip easily back into a caretaking role which they found hard to break out of (P.C., G.A., M.L.)

In only two cases was the relative's role particularly constrained. In the first, case 3, mentioned above, B.K.'s wife's lack of cooperation, due partly to her fantasy of him returning to his old self, may have impeded his progress and threatened his motivation to maintain his progress. In the second, Case 7, T's mother was looking after his father, (who suffered from Alzheimer's) full-time, and despite her intentions, was unable to take on the responsibility of co-therapist for her son, except to a very limited degree. These cases demonstrate two problems which can complicate

the relative's role as co-therapist. In such situations, it would seem clinically justifiable to tackle the origins of the stress first, and/or see the patient on his/her own.

As a Source of Information

Relatives also proved to be valuable sources of information although primarily in discussions during clinical sessions rather than on the formal measures. They provided information regarding a) the difficulties and successes patients met with in practising memory strategies and b) the degree of insight the patient had into his/her deficits, and any changes in this over time and c) the emotional climate the patient and family were living in, for example, to what extent other stresses were contributing to treatment progress. For example, in case 4, virtually no information was provided by HJ himself about the lack of communication and conflict in his marriage, nor of the absence of his wife's support in his use of the memory strategies. In another case, 5, the patient's wish to appear to be coping well, together with her extremely poor memory, led her often to confabulate and give details of activities which she had in fact avoided or forgotten to carry out. Only by her mother's information could AB's disordered and avoidant day to day life become a subject of treatment discussed by all involved, and thus reduce her denial.

Other issues highlighted by the relative's involvement included those associated with the stages of grief (Kubler-Ross, 1968). Lezak (1986) has described the role which these stages may play in the timing and aims of treatment and these seem very relevant to memory rehabilitation. Among these were 1) bargaining, where the treatment is agreed to in order to help make decisions about future compatibility (Cases 3, 9 and 10), usually in the presence

of unrealistic expectations; 2) role reversal, where decision making has been taken on by a previously dependant number of the family (Case 3 and 9), 3) guilt, already mentioned above, sometimes based on irrational feelings of responsibility. These issues are detailed in the literature on grief and bereavement (Kubler-Ross, 1968), and have been found in previous studies of the families of brain injured individuals (Lezak, 1986). Their occurrence here suggests that they arise even in treatments where the main focus is on memory rehabilitation and therapists need to be aware of the dynamics involved from an early stage so that they can be recognized and discussed.

It is clear in this study, from both formal and informal measures, that the relative's state of mind and well being is just as important as those of the patient in order for treatment to progress. Families in this study were given very little support outside their immediate family. Although most had been involved in Headway to some extent at some point, many felt they had 'moved on' from the group, yet acknowledged the need for support and were very much on their own. Finally, although the relative's role as a source of information is important, it should not be overestimated or seen as the only valid source of information. The discrepancy between the relative's and patient's views is not necessarily evidence of poor insight or denial, but may reflect a) the perceptions of a relative who is over stressed or b) a patient who is keeping problems hidden from relatives. This was noted to a mild extent in a few cases, but particularly so in case 7, in which both characteristics were vividly demonstrated. Therefore in a family-based program should always provide the opportunity to offer parallel forms of questionnaires to both patient and relative and for each participant to discuss concerns separately.

Summary and Conclusions

The purpose of this study was to determine whether severely head injured out-patients could be trained to successfully use a set of mnemonic strategies devised and adapted from the literature on memory rehabilitation. A key element in treatment was the role of relatives, who were trained in the use of the strategies in order to act as co-therapists to aid generalization to day to day settings.

The results show that patients can learn to use simple memory techniques and maintain benefit after treatment has ended. Only two of the ten patients were clear failures. The study also found that relatives were, in the main, able to offer a valuable role in mnemonic training. Their role was two-fold, and included a) acting as co-therapists, by actively participating in treatment sessions and then prompting the patient to use the techniques in other settings and b) acting as a source of information to help focus on treatment aims and provide insight into emotional and behavioural problems which were potential obstacles to treatment. The use of clear documentation describing the use of each technique as it was introduced appeared to facilitate their role.

The benefits of alleviating day to day memory problems reported by patients and relatives did not directly reduce the degree of psychosocial stress they experienced. There was considerable variation between individuals, with some showing clear improvement in mood and reduction in subjective burden, while others showed persisting signs of stress.

Lack of insight and denial appeared to be particular obstacles to rehabilitation. Although these characteristics

were present in some degree, particularly initially, even in those patients who responded well to treatment, in the two failed cases, however, these were found in extreme degrees. In one case, lack of insight was part of a constellation of features associated with frontal damage and in the other case psychological denial related to overwhelming stress and failure to accept intermediate goals.

Features which seemed to facilitate progress included readiness to accept compensatory memory aids and moderate agreement between patient and relative on the nature and degree of the memory problem. Even when these two features were only present to a limited degree initially, patients tended to succeed with the methods, and appeared to gain insight as treatment progressed. Neuropsychological status itself did not appear to be a barrier to treatment - psychological and behavioural problems were more likely to hinder progress.

The foundations for this study lie in the careful single case studies in memory rehabilitation carried out over the past decade which has aimed not at restitution but at retraining or compensatory methods aimed at real-life problems (Wilson, 1987, Soniberg, 1990). It has, however, set a wider focus by involving relatives actively in treatment, in an out-patient setting, as the valuable role of relatives has already been well established (Rogers and Kreutzer, 1984). As with these earlier studies, it was found here that a flexible approach, with problems being dealt with as they arose was more appropriate than a prescriptive fixed agenda would have been. Yet it was still clearly necessary to have a structure to counteract the apathy or resistance of the patient as well as the helplessness of relatives who may feel emotionally and physically spent.

Recently more studies aimed at reducing everyday memory problems have been published, and the results have been encouraging (Koning-Hanstra et al, 1990). The effectiveness of memory techniques found in this study adds to the growing evidence that memory rehabilitation is proving to be relatively unproblematic, now that the focus is on mnemonics (e.g. Wilson, 1987). However, this study suggests that it needs to be geared towards generalisation and day to day problems. In order for this to be practicable, the relative's role cannot be overlooked.

Relatives were more often than not, not only willing to help patients but actually felt the need to be doing something. Memory rehabilitation is a practical and manageable way for them to do so, and may be the best entry point for some to further, more demanding rehabilitation. Once memory rehabilitation has ended, even if successful, the question 'now what?' remains. The next likely step is a move towards meaningful occupation, which still remains out of reach for many patients, and there remains a dearth of appropriate community-based settings (Yvlisaker, 1987).

Finally, this study demonstrates that memory rehabilitation does not occur in a vacuum and that psychosocial and family factors must not only be considered but actively included as part of the therapeutic framework. Families were clearly very stressed, both before and after treatment. This suggests that other areas of need, which are not currently getting much attention in rehabilitation research, including marriage, dependence, and occupation. By including the family in memory rehabilitation, we can not only maximize the patient's ability to benefit from treatment, but also provide support to the relative and enable them to find further sources of help.

ADDENDUM TO THE DISCUSSION

Values & Limitations of the Subjective Memory Checklist

In view of the lack of real-life prediction available from tests, and the evidence that patient's retrospective questionnaires are not valid (Sunderland, Harris and Baddeley, 1983), the main outcome measures in this study are checklists of memory failures, recorded at the time of the failure, and comprise items familiar to head-injured patients. Sunderland, Harris and Baddeley (1983) reported that contemporaneous checklists bore a closer relationship to psychometrics and injury severity, and that patient and relative checklists were in fairly good agreement. Items included in the checklists were based on items in which our patients most often reported failures, comprising a similar but shorter list to that of Sunderland et al. They thus provide a simple, dependent measure for research, which was unstressful for patients and relatives to use. This research, which was unstressful for patients and relatives to use. This research was on the effectiveness of mnemonics in the day-to-day setting, and a similar use of checklists based on EMQ items was applied by Wilson in evaluating mnemonic strategies (Wilson, 1987.
Concurrently, the memory checklist (MCL) can be used to target problems for remediation, e.g. losing concentration while reading would suggest that PQRST might be helpful. Thus, the MCL can help identify day-to-day difficulties, and problems which persist or relapse during treatment. Its value is in its brevity and relevance to the patient, which enables it to be completed regularly by minimising the interval between forgetting and recording.

The main limitation of the MCL is the problem of under-reporting. This is most likely to be the result of: 1) forgetting to record, or lack of insight or denial on the part of the patient, and 2) on the part of the relative, a failure to realise memory failures had occurred because there was no overt (behavioural) sign: for example, lapses of which only the patient could be aware (i.e. losing concentration when reading). The task of recording is, of course, a memory task itself (Sunderland et al, 1983) and may be compounded by the absence of a strategy or cue to remember failures. Despite efforts to minimise the failure to record (e.g. by ensuring that the interval between forgetting and recording the failure is not too long), the nature of the task makes it very likely that both memory questionnaires and checklists are providing an underestimate if kept solely by either patient or relative, and there may be failures (subjective or objective) which may not be noticed. As treatment progresses, and possibly more demands are made on the patient's memory, an increase in the number of failures may be observed. Increased insight as treatment progresses may also result in more failures being recorded, and patients may comment that they had been forgetting, but had failed to acknowledge it. But while an increase in recording may initially appear, this tends to decline with treatment as mnemonic strategies compensate for the greater demands on memory. Lam's study lends qualified support to the hypothesis that such awareness of deficits actually results in greater response to treatment (lam et al, 1988).

Clinical and Research Implications

The treatment method used in this study has aimed to

introduce simple, ecologically based (i.e. 'real-life')memory techniques to patients, in a way that maximises the opportunity for generalisation, by involving relatives as co-therapists. By using a single-case design, it has been possible to identify some of the characteristics which indicate that a particular patient will respond to the approach. The main clinical implication would therefore seem to be that it offers a structured treatment programme, which is largely acceptable to patients with significant memory problems, and leads to a reduction of practical difficulties which undermine confidence and are a source of frustration. In addition, the fact that the approach involves working closely with both patient and relative allows significant emotional problems experienced by either the patient or relative to be identified, and either tackled or referred to another professional. Perhaps most importantly, the involvement of a relative to prompt and support the patient in their use of techniques, helps techniques to become habitually applied in the 'real-life' (rather than clinical) environment.

Regarding implications for research, the study provides an instance of the value of using single-case methodology in studies of head injured patients. The close attention paid to each case helps features to be identified which provide indicators or barriers to good outcome, and thus to provide a basis for future studies. The nature of the study also has important indications for further research. The role of relatives, although often mentioned as a valuable aspect of treatment, has yet to become the basis for other systematic studies involving memory rehabilitation. Further studies involving a family-based approach would be valuable in lending further weight to the suggestion, in

this study, that families can serve a valuable role. The use of a set of simple mnemonic strategies, back up byinvolvement of a relative, may be expected to offer valuable help to other brain-injured populations, for example, stroke victims, or patients in the early stages of a dementing process. The importance of information and support to relatives of such patients is often noted, but practical help is often very limited. it would therefore seem worthwhile to consider the effects of this approach in these populations, whose recover process can be quite distinct from that of the head-injured. Within the head injured population, there would be value in extending the present work to group designs with larger numbers of cases, although the value of initially studying small numbers in a detailed single case design should not be forgotten.

The Relationship of This Work to Previous Studies

Cognitive remediation strategies have tended to focus on direct re-training methods, although these have been found to have disappointing results (Wilson and Moffat, 1992). Although recent studies have become increasingly directed to the everyday problems (e.g. Wilson, 1987), there continues to be a tendency to focus on component skills, rather than the range of everyday problems which head injured patients experience (Sunderland et al, 1983). Given that the aim of ecological approaches is to achieve greater generalisation that has been found on laboratory based studies, it is perhaps surprising that none has formally evaluated the role of the relative, a key person in the patient's everyday environment, as a possible contributor to achieving this aim. This study is therefore

distinct in two clear ways: 1) it introduces to the patient a 'package' of mnemonic techniques, aimed at reducing a range of memory failures that the patient is currently experiencing in everyday settings, and 2) the relative plays a key role in treatment, both as a source of information and as a co-therapist, to aid generalisation. Although the value of relatives has been cited in several studies (e.g. Rogers and Kreutzer, 1984), this study formally evaluates a memory rehabilitation programme which actively involves relatives.

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APPENDICES

Appendix 1 - Repetition Test

NAME: _____ DATE: _____

REPETITION

1.	Bed	2
2	Nose	2
3	Pipe	2
4	Window	2
5	Banana	2
6	Snowball	4
7	Forty five	4
8	Ninety five percent	6
9	Sixty two and a half	10
10	The telephone is ringing	8
11	He is not coming back	10
12	The pastry cook was elated	10
13	First British field artilery	8
14	No ifs ands or buts	10
15	Pack my box with five dozen jugs of liquid veneer	20

Maximium Score = 100

Patients Score =

Appendix 2

QUESTIONNAIRE FOR PATIENTS

The following questions are to help us find out how you are progressing, by getting information about any changes or symptoms you have been experiencing since your injury.

1. Name _____

2. Today s Date _____

please turn over

Hospital Use:

H.I F.U.

(1-3)

The questions which follow are about your health over the last few weeks, compared with your health before the injury.

Do you suffer from:

(For each question, circle the answer which applies)

16. Irritability	no change	rather worse since injury	much worse since injury
17. Outbursts of temper	no change	rather worse since injury	much worse since injury
18. Outbursts of violence	no change	rather worse since injury	much worse since injury
19. Difficult speaking (eg. slurred speach stammer)	no change	rather worse since injury	much worse since injury
20. Difficulty finding the right word	no change	rather worse since injury	much worse since injury
21 Difficulty under standing what words mean (not due to poor hearing)	no change	rather worse since injury	much worse since injury
22. Poor concentration	no change	rather worse since injury	much worse since injury
23. Depression	no change	rather worse since injury	much worse since injury
24. Childishness	no change	rather worse since injury	much worse since injury
25. Sudden changes in mood	no change	rather worse since injury	much worse since injury

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Hospital Use:

16 [ ] 17 [ ] 18 [ ] 19 [ ] 20 [ ] 21 [ ] 22 [ ] 23 [ ]

24 [ ] 25 [ ]

For each code L to R = 0 1 2 (17-26)

please tick one

30. Have you suffered any fits since discharge from hospital?

- none ☐
- occasional ☐
- regular ☐

31. Do you need to take tablets to prevent fits?

- no ☐
- yes ☐

32. As a result of the injury, are you disabled to the extent that stick, crutches, wheelchair, etc. are needed?

- fully independent that is no aids and no difficulty getting about. ☐
- get about without aids, but with some difficulty. ☐
- need stick/crutch ☐
- confined to wheelchair, can move self in it. ☐
- confined to wheelchair, needs pushed ☐
- confined to bed ☐

Hospital Use:

30 ☐ 31 ☐ 32 ☐ (1 to 6)

Code 0. 1 (2)

(36-38)

please tick one

37. What was your occupation before injury?

- working full time
- working part time
- housewife
- student
- retired
- unemployed
- unfit for work

38. What is your NORMAL line of employment? please state.

_____

39. What is your occupation now?

- working full time
- working part time
- housewife
- student
- retired
- unemployed
- unfit for work

Hospital Use:

37 [ ] 38 [ ] 39 [ ] (1 to 7)

(43-45)

P Q R S T RECORD SHEET

This is a sheet where you can record your progress as you practice PQRST.

1. Note the subject of the article.
2. Rate on a scale of 0-10 (0 = no recall, 10 = total recall) how well you could remember the material when "tested", whether by yourself or by a relative.
3. If any additional reading was carried out at other times, eg. reading at bedtime, make a note of this.

Date/ Time	Subject of Article	Rate recall 0 - 10 ½ hour later	Rate 0-10 1 hour	Rate 0-10 24 hours	Other reading (list no. pages if book)

(after F P Robinson, 1970)

SUMMARY:

THE EFFECTS OF SEVERE HEAD INJURY

This summary of the effects of severe head injury is to help you understand what has happened and to help you take part in the out-patient remedial programme we are offering at this hospital.

IMMEDIATE EFFECTS

If an injury is severe, the injured person is usually knocked unconscious. As a result, he/she will not be able to remember the moment of injury - ever. This is because the brain fails to store information in the memory. Events for a period BEFORE the impact are lost (this is called "retrograde amnesia"); and events for some time AFTER injury are also not stored (this is called "post-traumatic amnesia" or P.T.A.).

The failure to remember what happened at the time of injury is therefore not intentional - it can't be helped. And since this information wasn't stored in the first place, no amount of "jogging" the memory will make the injured person GENUINELY remember it.

The brain suffers some INJURY at the time of impact. The hospital doctors and nurses try to prevent, so far as possible, further damage from brain swelling, formation of blood clots, and so on. At this time the patient may have tubes and drips attached, may have to undergo surgery, and the immediate concern of the family is for the patient's survival.

Other problems which arise in SOME cases include:

APATHY

Some patients have little interest or "drive". Nothing seems to matter to them. They are quite content to sit around staring at the wall. This can be infuriating for family members, but it must be remembered that this isn't deliberate - it's often a direct result of injury to the front part of the brain. The only thing that seems to overcome this inability to get going may be a fright or something that makes the patient angry. Sometimes relatives feel hurt by what looks like indifference or laziness, but "getting started" is a genuine problem for the patient.

LACK OF INSIGHT

The term "insight" refers to being AWARE of our own limitations. Head-injured patients sometimes lose this awareness. For example, a patient may think his memory is fine, and that he's calm and reasonable. But in fact his memory may be poor, and he may be very bad tempered.

BEING OUTSPOKEN

Some patients speak "out of turn" perhaps swearing, or boasting, or being cheeky and provocative. This sort of behaviour is sometimes referred to as "disinhibited" and is very difficult for families to cope with. It is embarrassing and may get the patient into trouble.

HOW MUCH IMPROVEMENT CAN BE EXPECTED?

The OLD-FASHIONED view is:

Patients continue to improve for 6 to 12 months, but rarely for much longer. Whatever they're like at the end of that time is how they'll remain long-term.

More UP-TO-DATE evidence suggests:

Further gradual progress is likely in those who are doing well by about 1 or 2 years after injury. Those who are doing less well (for example, are still not fit for work) are less likely to make further gains.

BUT

Both of the above statements are based on studies of patients who usually had little or no rehabilitation.

WE DON'T KNOW YET FOR SURE HOW MUCH CAN BE ACHIEVED BY IMPROVED REHABILITATION. BUT IT LOOKS AS IF FURTHER IMPROVEMENTS ARE POSSIBLE FOR MOST PATIENTS.

WHAT HELP MAY BE AVAILABLE?

Unfortunately, there is no comprehensive rehabilitation available in Britain at the present time. What you CAN do is ask for help with PARTICULAR problems. The list of health care staff which starts on the next page is to help you do this.

SPEECH THERAPIST

While a minority of head injured patients suffer speech or language problems, those who do should see a speech therapist. He/she will carry out a diagnostic assessment to see if treatment or communication aids would be of help. If necessary, they will help patients with speech or language difficulties to try to readjust to the demands of work etc.

OCCUPATIONAL THERAPIST

Patients who have forgotten how to do simple household tasks may be helped. Also, occupational therapists try to prepare patients for return to work by building up the amount of time they can concentrate on tasks.

SOCIAL WORKER

They can help you to find out what benefits you should be receiving and give other practical advice. The Social Work Department also runs Day Centres which some patients benefit from attending.

YOUR FAMILY DOCTOR (G.P.) OR A MEMBER OF HOSPITAL STAFF CAN DISCUSS WHETHER IT WOULD HELP TO SEE ANY OF THE ABOVE, AND CAN ALSO MAKE THE NECESSARY ARRANGEMENTS.

There are other sources of help too, listed on the next page:

WHAT QUESTIONS SHOULD I ASK HOSPITAL STAFF?

Ask about anything that concerns you.

For how long will the patient improve?
Will he/she be able to resume work, and when?
How should I handle temper outbursts/memory failures etc?
Is there a risk of fits?
Is it safe to take up sport? Or take alcohol?
Etc.

People often think of questions AFTER they have seen the doctor or other member of staff.
WRITE YOURS DOWN SO YOU DON'T FORGET.

And, DON'T BE AFRAID TO WRITE DOWN THE ANSWERS. The doctor won't mind if you say something like:
"I hope you don't mind. It's just that it's easy to forget when there's a lot on your mind".

PHONE NUMBER FOR "HEADWAY":

Neuropsychology Unit, Dept Clinical Neurosciences, Western General Hospital, Edinburgh EH4 2XU

Appendix - 5

COPING WITH YOUR RELATIVE'S MEMORY PROBLEMS

****Remember the importance of routine....** in regard to where things are kept, when things are done etc. Introducing changes one at a time will prevent you from feeling stifled and keep your relative from becoming confused.

****As your relative learns to use the Diaries, PQRST etc....** he/she may still be in the habit of asking others directly for information. First encourage him/her to check his/her own sources for the answer. Second if he/she still doesn't know then try to respond by cueing, or hinting rather than giving the complete answer. Finally if this doesn't work after a few times, then give the answer.

****Try to encourage your relative's efforts....** even if he/she is still forgetting some things. Remember, you're both learning new habits. It takes time and practice.

****Help your relative develop social confidence....** by drawing him/her into conversation with others, eg: "what do you think about that?"

****Aim to pick up activities enjoyed prior to the injury....** whether as a family, or the patient on his own or with friends. It's important to "take risks" in order to feel a sense of accomplishment.

Appendix 6 - Social Skills Handout (CHAT)

C H A T

The letters CHAT are a reminder of 4 steps that may be used if you find it difficult to join in a conversation

C - CATCH their attention

If you forget a person's NAME or WHO HE OR SHE IS, don't bluff or ignore them..... *Say something like*

- *"Since my accident, there are a few blanks in my memory, I just can't get your name" or*
- *"I'm sorry, I can't place you".*

If you can't keep track of a conversation, because it's TOO QUICK or there's BACKGROUND NOISE..... ***Say something like***

- *"I'm sorry, I missed what you said. Could you slow down a bit?" or*
- *"I can't hear so clearly now, would you say that again?"*

H - HANDS eyes and voice

If you're left out of a conversation, maybe it's because you don't LOOK interested..... ***Remember HANDS, EYES and VOICE***

- *your HANDS and posture can tell others that you want to join in - don't "shut them out"*
- *your EYES can show you're interested - LOOK at the person who's speaking*
- *your VOICE is important - use pitch to sound interested*

A - ASK questions

If you're not confident of what to say..... ***ask OPEN questions***

- *Open questions invite the other person to tell you something, not just say "yes" or "no"*
- *eg NOT "Have you booked a holiday?"*
  BUT "Where are you going on holiday?" "Why do you like Majorca?"

T - Prepare TOPICS

If you can't remember much to contribute to a conversation, or aren't sure of you facts..... ***have some topics up your sleeve.***

- *Use DAS to remind yourself of what you've been doing*
- *Use PQRST to remind yourself of what's in the news/sport/etc*
- *Use shared interests as topics where possible*

C H A T RECORD FORM

Use this form to note down occasions whem you have used CHAT. It may help you to look back and see the best ways of using CHAT

OCCASION .....

How did you *catch their attention?*

How did you use your *hands, eyes and voice?*

What did you *ask* about?

What *topics* did you talk about?

HOW WELL DID YOU HANDLE THE CONVERSATION? .....
(0 = badly to 10 = very well)

NOTE ANY LESSONS FOR THE FUTURE

OCCASION .....

How did you *catch their attention?*

How did you use your *hands, eyes and voice?*

What did you *ask* about?

What *topics* did you talk about?

HOW WELL DID YOU HANDLE THE CONVERSATION? .....
(0 = badly to 10 = very well)

NOTE ANY LESSONS FOR THE FUTURE

A C T

The letters 'ACT' are to remind you of the steps to follow if you have trouble STANDING UP FOR YOURSELF.

♦♦♦♦♦

A - ASK for help

If you need help or information, ASK for it directly ..... don't wait for someone to offer it.

e.g. "Which way is it to the bus stop?"
"I've lost my DAS. Can you help me look for it?"
"I didn't understand that. Would you explain it again?"

C - COMMUNICATE your views

Don't let yourself be ignored or forgotten.

COMMUNICATE - let people know what you think.

If you disagree with what's being said,
don't bottle up your annoyance .....
instead, COMMUNICATE - express your views.

e.g. "I think it's unfair of you to stay at the pub when I've got dinner ready here".

T - TURN DOWN requests ... if it's something you don't want to do.

If you are asked to do something and
.... you don't *want* to do it

.... or you *can't* do it because you've too much on your plate

TURN DOWN THE REQUEST - SAY "NO!" and explain why.

e.g. "I've got three orders to send out already... I can't do any more today".

"I'd rather not move to the main workshop... I can't concentrate well if it's noisy".

STOP! LOOK! and LISTEN!

This is to remind you about:

- how to INTRODUCE YOURSELF, and
- how to HOLD A CONVERSATION with other people.....
  especially with strangers.

♦♦♦♦♦

STOP!

Stop and ask yourself:

Do I know this person?

Do I need to introduce myself?

If so, say something like:

"Hello, I'm Jimmy Smith (or whatever your name is)......
I'm pleased to meet you" ...*OR*...

"Have we met before? Could you tell me your name again?"

LOOK!

Look ahead! Think about the effect you may have on others.

Be careful how you pay a compliment or criticize someone.

* They may not like "jokes" or suggestive remarks....
  they may be embarrassed or angry.
* They may not share your views....
  you could end up in an argument or fight.

LISTEN!

Listen carefully to what others say to you.

When you've heard what they have to say....

* Reply to WHAT THEY SAID - what you say should follow on.
* TAKE TURNS to speak - don't just go on and on, but let the other person have as much chance to talk as you.

STICK TO THE TOPIC and you can have an enjoyable conversation.

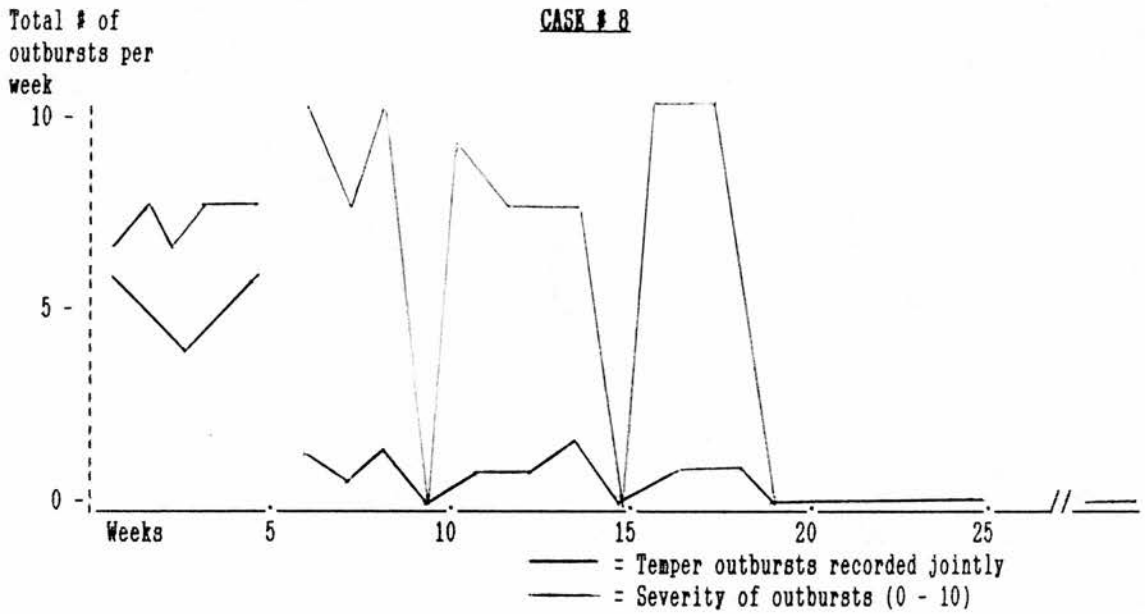
Find out what the other person has to say
Try to remember their name
and
Try to remember what they told you.

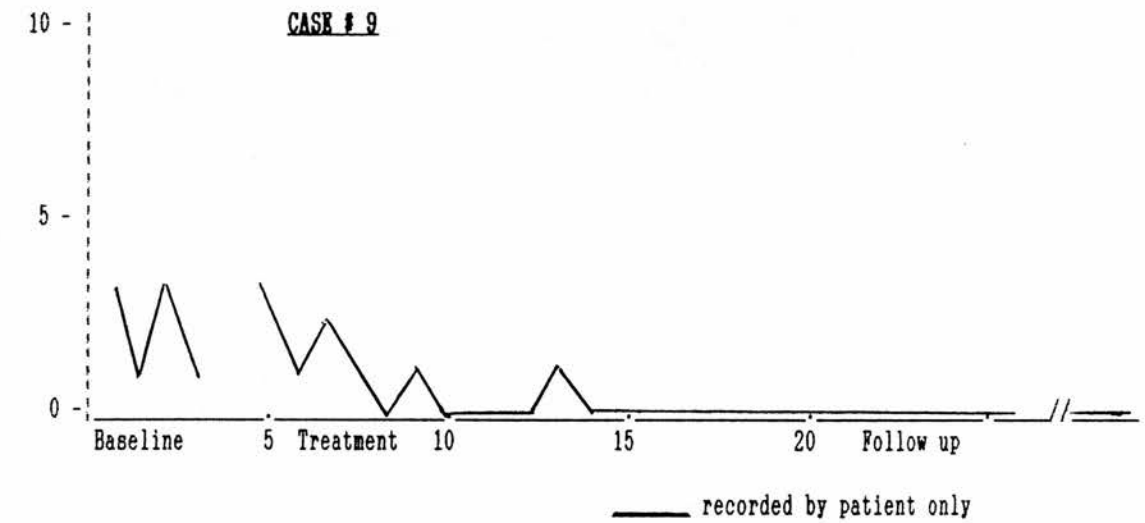
"STOP! LOOK! and LISTEN!"

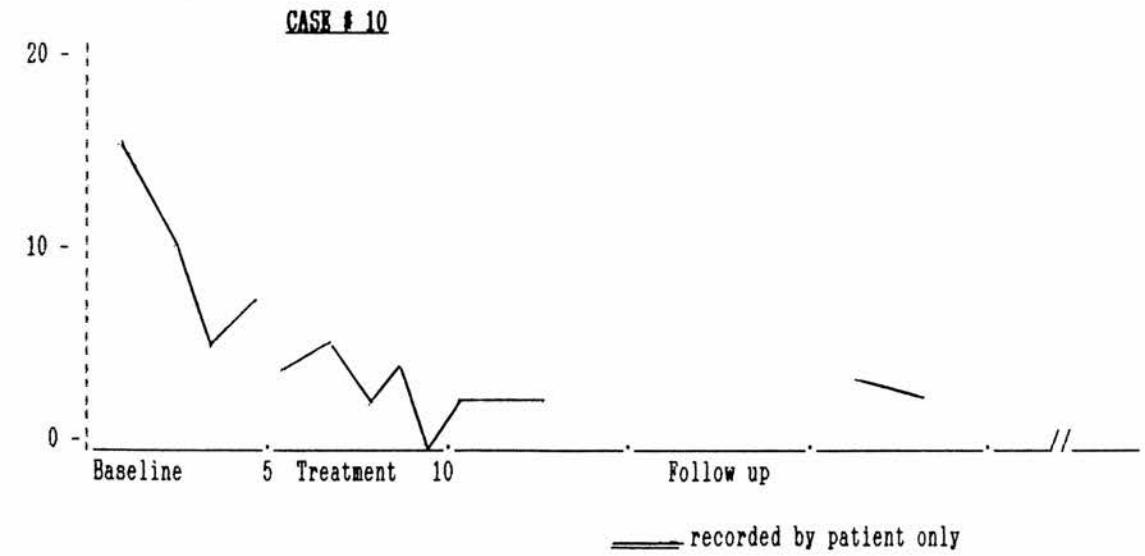
WHENEVER YOU MEET SOMEONE, GO THROUGH THIS DRILL IN YOUR HEAD

Appendix 9 - Temper Data for Cases 8, 9 & 10

TEMPER







Appendix 10 -- Anger Handout

A N G E R

The letters ANGER are a reminder of 5 steps to help to CONTROL YOUR TEMPER.

A - ANTICIPATE

ANTICIPATE the situations when you are likely to lose your temper.

Use your ANGER RECORD FORM to recognise.....

- What *times* you're at risk of getting angry
- What *places* you're at risk of getting angry in
- What *people* you're most likely to get angry with.

N - NOTICE

NOTICE.....when you're in a "risky" situation

AND.....when you start feeling TENSE or ANNOYED (i.e. about to lose your temper).

G - GO THROUGH YOUR 'TEMPER ROUTINE'

GO TEROUGH YOUR "TEMPER ROUTINE".....

1. Start your RELAXATION exercises
2. Start your BREATHING exercises
3. Try an ALTERNATIVE way of handling the situation.

E - EXTRACT YOURSELF from the situation

If necessary, EXTRACT yourself from the situation.....GO AWAY!

but.....don't just drop the matter. When you're calm again, go back and talk through the problem.

R - RECORD how you coped

RECORD how you coped.....what lessons can you learn for next time?

Use your ANGER RECORD FORM. Learn from your mistakes !

(GGU Heminway& Hicks. Family Based Head Trauma Rehab Study. 1997
Neuropsychology Unit, BRI, Western General Hospital, Edinburgh.

COPING WITH AN ANGRY RELATIVE

**To disarm a stream of angry words or behaviour--*

--*get the person's attention*, e.g. by repeating their name, or saying something like "listen to me" or "stop that". Repeat it loud enough to be heard.

--*make eye contact*, and immediately follow through with a brief message of what you want to communicate, e.g. "I know you're angry. We'll talk later, when you've calmed down", or "I know you're angry but I'm frightened when you're like this."

--*leave the situation* if he/she continues to be aggressive. Instead of hearing the angry person out, it may be more constructive simply to go away.

**Watch your own angry feelings.*
Aim to communicate, Don't shout back, but Don't stay silent.
Put your message calmly.

**Avoid angry discussions when either of you has been drinking alcohol.*
DO arrange to talk at the first appropriate opportunity and stick to this arrangement.

**Try not to take their anger personally.*
You didn't "make" them angry. The injury has made them more likely to flare up.

**Acknowledge the other's feelings,*
e.g. "I know you're angry...". Don't cut them off or deny their feelings.

**Express your own feelings clearly.*
"I feel upset when you shout at me" is more accurate than "Shut up!" or saying nothing at all.

(C)A Hicken/U McKinlay Family Based Head Trauma Rehab Study
Neuropsychology Unit, DSN, Western General Hospital, Edin

Appendix 12

RECORD OF ANGER EXPERIENCES

DATE/ TIME	SITUATION Where were you? What were you doing at the time?	BEHAVIOUR What did you do or say?	SEVERITY Rate the degree of your anger (1-10) 1 = very mild 10 = severe	OUTCOME What happened then? Rate how well you coped 1 = very poorly 10 = very well	ALTERNATIVES How would you handle it next time?

A N G E R WORK SHEET

Use this form to note down occasions when you have used ANGER. It may help you to look back and see the best ways of using ANGER.

OCCASION .....

How did you ***anticipate*** that you were likely to lose your temper?

How did you ***notice*** you were getting tense or annoyed?

How fully did you use your ***temper routine***? (Breathing /Relaxation / Alternatives).

Did you need to ***extract*** yourself from the situation? (eg: left the room / apologised etc).

BE SURE TO RECORD EACH SITUATION ON YOUR ANGER RECORD FORMS AND NOTE ANY LESSONS FOR THE FUTURE.

OCCASION .....

How did you ***anticipate*** that you were likely to lose your temper?

How did you ***notice*** you were getting tense or annoyed?

How fully did you use your ***temper routine***? (Breathing /Relaxation /Alternatives).

Did you need to ***extract*** yourself from the situation? (eg: left the room / apologised etc).

BE SURE TO RECORD EACH SITUATION ON YOUR ANGER RECORD FORMS AND NOTE ANY LESSONS FOR THE FUTURE.